

“IT WOULDN’T CHANGE A THING”: THE ROLE OF IDENTITY POLITICS AND  
GENDER POLITICS IN MEXICAN-AMERICAN WOMEN’S DECISION-MAKING  
EXPERIENCES ABOUT PRENATAL TESTING

A Dissertation

by

LEANDRA HINOJOSA HERNANDEZ

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Chair of Committee,	Richard L. Street, Jr.
Co-Chair of Committee,	Tasha Dubriwny
Committee Members,	Antonio La Pastina
	Joan Wolf
Head of Department,	J. Kevin Barge

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## ABSTRACT

This dissertation explores Mexican-American women's experiences with prenatal testing, more specifically the amniocentesis procedure. Utilizing health communication theories and Chicana feminist theories as my theoretical lenses, I explored the social construction of the amniocentesis procedure for Mexican-American women, as well as the role of their family members and healthcare providers in their decision-making processes. An intersectional feminist thematic analysis was conducted of 30 semi-structured, in-depth interviews with Mexican-American women between the ages of 30 to 45 in Houston, Texas and San Diego, California.

Ten themes emerged from the data and presented a portrait of the information processing and decision-making processes that the participants went through as they deliberated whether to undergo the amniocentesis procedure. Of the 30 participants, only one underwent the amniocentesis procedure; the other 29 participants refused the amniocentesis procedure because it would not change the outcome of their pregnancy, because they did not see a need for the information the amniocentesis could provide, and because their families would support them in their decision to not abort a child with a disability. Moreover, participants noted that their spouses and family members were very encouraging during their decision-making processes, which further solidified their decision to reject the amniocentesis procedure. Lastly, participants spoke of their physicians' role in the amniocentesis, and most noted that their physicians supported their decision. Participants preferred physicians who spoke to them in a caring manner and disliked when their physicians did not explain health-related information with them

or take the time to establish a relationship with them.

These findings provide a new snapshot of what the amniocentesis experience is like for Mexican-American women. Participants refused the amniocentesis, but not for reasons that have been supported in past academic literature. Moreover, participants provided a new conceptualization of what a “healthy baby” is and looks like—a fetal anomaly or congenital disorder was not framed as negative, unhealthy, or undesirable. This conceptualization of “what a healthy baby is” was situated within sociocultural factors such as family support, strong spiritual values, and a maternal/fetal fusion with their children. Lastly, given the delicate nature of this prenatal procedure, physicians should be more empathetic and more caring. This communication style would make patients more comfortable and create a more satisfying healthcare experience.

## DEDICATION

This dissertation is dedicated to Maria del Pilar Contreras Montoya, my grandmother, and Ernestine Hinojosa Hernández, my mother, for blessing my life with their selfless and unconditional love and teaching me about the beauty of motherhood; Froilán Antonio Hernández, my father, Alexandria Hinojosa Hernández, my sister, and Pedro Luís Arturo Ortega, my husband, for their never-ending support and love; and to my participants, for taking the time to share their life experiences, stories, joys, and tears with me. I am forever grateful for their presence in my lives.

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## CHAPTER I

### INTRODUCTION

A woman's pregnancy can simultaneously be one of the most exciting and uncertain times of a woman's life. It can be characterized by much uncertainty about morning sickness; bodily changes; the health of the baby and mother; negotiating prenatal care and testing decisions with relational partners, family members, and healthcare providers; and birthing methods, among other topics (Davis-Floyd, 2003; Martin, 1987; Rapp, 2000). Moreover, a woman's cultural, ethnic, and religious backgrounds and upbringings can also shape pregnancy experiences and have profound implications for pregnancy-related decisions and decision-making (Fordyce & Maraesa, 2012; Galvez, 2011; Martin, 1987; Rapp, 2000).

For the last three decades, scholars in fields such as communication, anthropology, and women's studies have explored pregnancy experiences and pregnancy decision-making as affected by one ever-changing, key factor: the creation of and increase of reproductive technologies. The overarching label "reproductive technologies" is an umbrella term for an array of prenatal screenings and testings including but not limited to ultrasounds, chorionic villus sampling, and amniocenteses. Foundational scholars such as Rayna Rapp (1988; 1994; 2000) and Barbara Katz Rothman (1986), as well as more contemporary scholars such as Carole H. Browner and H. Mabel Preloran (1999; 2003; 2004), have studied the role of reproductive technologies in women's pregnancies and have consistently argued that despite reproductive technologies' advantages and disadvantages, one thing is certain: women's

pregnancy experiences have been and will forever be changed because of the ability to visualize and test the fetus (Katz Rothman, 1986; Rapp, 2000).

Making the decision to undergo prenatal testing is perhaps one of the most difficult decisions a woman can make during her pregnancy. Prenatal diagnostic testing provides information about fetuses' chromosomal makeup, letting future parents know if their child has Down syndrome or other congenital disorders. Pregnant women are encouraged to have a "triple screen" test, which tests for trisomy, Down syndrome, and neural tube defects (Hunt & de Voogd, 2005; Hunt, de Voogd, & Castaneda, 2005). If a positive diagnosis occurs, an amniocentesis is recommended to further assess the genetic defects at hand (Hunt, de Voogd, & Castaneda, 2005). This process typically sets off a domino effect, as a positive triple screen test could lead to an amniocentesis, which could lead to information about the fetus' genetic abnormalities, which ultimately results in one of two decisions: life with a (potentially) disabled child or an abortion.

As Rapp (1988) has noted, undergoing prenatal testing makes women and their spouses "moral pioneers" as they make the life-changing decision to either abort the fetus or let the pregnancy come to term, making them "moral gatekeepers" of who is worthy to live on this planet. Considering the delicate and complex nature of this decision, it is imperative that women and their physicians (whether the genetic counselor or another clinician) engage in informed and shared decision-making and that women have adequate prenatal counseling, ensuring that they can make the most informed, comfortable, and confident decision regarding whether or not to undergo prenatal testing.

As such, the goal of this dissertation is to untangle and explore the pregnancy experiences of second- and third-generation Mexican-American<sup>1</sup> women, with a focus on their decision-making with spouses and healthcare professionals about prenatal testing and amniocentesis. How do they perceive their communicative encounters and exchanges with their spouses, family members, and healthcare providers about prenatal testing information? How do they perceive their religion and relational gender politics contribute to, shape, and affect their decision-making? A multitude of scholarship has explored immigrant Mexican women's pregnancy experiences while here in the U.S. and their struggles with reconciling their familial and cultural traditions with the U.S. healthcare system (Galvez, 2011; Galvez, 2012), Mexican women's pregnancy experiences in Mexico (Howes-Mischel, 2012; Smith-Oka, 2012), and even American discursive constructions and stereotypes of Mexican and Mexican-American women as "hyper-fertile baby machines who breed like rabbits" (Gutierrez, 2008); however, no scholarship has explored second- and third-generation Mexican-American pregnancy experiences here in the U.S., their experiences of shared decision-making about prenatal testing with spouses and clinicians, and how they perceive their generational status and ethnicity shape their pregnancy beliefs, actions, and decision-making.

### **Rationale for This Study**

The Hispanic/Latino population is the largest growing minority in the United States. According to the Pew Hispanic Center (2011), the 2010 Census counted 50.5

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<sup>1</sup> I use the term "Mexican-American" as my participants' ethnic descriptor for uniformity in the text. I am aware that my participants chose to identify in a myriad of ways, and the terms they used to describe their ethnicity will be described in Chapters III & IV.

million Hispanics in the United States, making up 16.3% of the U.S. population. Furthermore, the Hispanic/Latino population in the U.S. grew 43% over the past decade and accounted for most of the nation's 56% growth (Pew Hispanic Center, 2011). Given that this population is the fastest growing minority group in the country, it is no surprise that there has been a surge in scholarship that explores Hispanic/Latino health issues and health outcomes. Research has explored Hispanic/Latino experiences with diabetes challenges (Caballero, 2005; Caballero, 2007; Umpierrez, Gonzalez, Umpierrez, & Pimentel, 2007), HIV/AIDS prevention barriers (Gomez & Marin, 1996; Nyamathi, Bennett, Leake, Lewis, & Flaskerud, 1993; Singer, Castillo, Davison, & Flores, 1990), cervical cancer (Chavez, Hubbell, Mishra, & Valdez, 1997; Coughlin, Uhler, Richards, & Wilson, 2003; Selvin & Brett, 2003); and even teenage pregnancy rates among Latina adolescents (Dogan-Ates & Carrion-Basham, 2007; Russell & Lee, 2004; Spear & Lock, 2003; Villaruel, 1998).

However, despite the fact that Mexican-American women account for approximately one in every seven U.S. women of reproductive age, there is a significant lack of research dedicated to exploring the breadth and depth of Mexican-American adult women's sexual and reproductive health (Chavez, 2004; Foulkes, Donoso, Fredrick, Frost, & Singh, 2005). Although a significant amount of research has explored the "Latina birth weight paradox," the phenomenon in which Mexican-born women have higher birth weights and more favorable birth outcomes than other racial/ethnic groups (Bender & Castro, 2000; Galvez, 2011; McGlade, Saha, & Dahlstrom, 2004), a scant amount of research has examined Mexican-American reproductive shared-decision

making challenges and experiences with their healthcare providers, especially those of second- and third-generation women in transition between culture.

Moreover, other factors that have not been thoroughly explored with regard to Mexican-American women's pregnancies are certain dimensions of one's culture, such as relational gender politics and religion, and the extent to which they and paternalistic healthcare efforts shape and influence pregnancy trajectories and decision-making. The scant research that does exist suggests that Mexican-American health experiences broadly are shaped by factors such as religion (Catholicism), language barriers, and gender roles including but not limited to *machismo*, *marianismo*, *simpatia*, and *familismo*; however, there is very little explication of the unique cultural and gender nuances that each Mexican-American woman experiences as she navigates her pregnancy and negotiates power and decision-making with healthcare providers. For example, Mexican-American sexual and reproductive experiences with husbands and partners are often characterized by gender-based power imbalances both while negotiating sexual encounters and also in pregnancy decision-making (Galanti, 2003; Harvey et al., 2002; Sable et al., 2009), but what about with their physicians?

Key ethnic concepts and norms such as *machismo* ("a cultural term for a set of identities and attitudes associated with the Hispanic concept of masculinity" [Caballero, 2011]), *simpatia* (the feminine cultural counterpart that emphasizes niceness and smooth, easygoing relationships [Gomez & Marin, 1996]), and *familismo* (the belief that women will put their family's needs above their own [Marin & Marin, 1991]) unequally position Mexican men as the sole decision-maker and Mexican women as the familial

martyr, often at the expense of their own health. However, what needs to be parsed out of this research is the extent to which relational gender politics affect women individually. How do different Mexican-American women experience these relational gender politics during their pregnancies, and to what extent? Do their experiences differ based upon their ethnic and cultural identification and class status? Are the gender norms and politics that are so oft described in academic discourses still very prominent in Hispanic/Latina pregnancies, and how are they negotiated and managed?

Academic discourses frequently portray Mexican-American patients as being Catholic (Vidal-Ortiz, 2010), fatalistic, and extremely dedicated to one's family (Hunt & de Voogd, 2005; Fisher & Groce, 1985), and although research that explores cultural and gender norm factors is indeed important, it is crucial that these patients are not stereotyped and essentialized. Within a healthcare context, Mexican-American women frequently encounter patient-provider stereotyping and culture clashing. The healthcare encounter is characterized by an interplay of many factors that complicate the decision-making process (Beck, 2001). Power pervades healthcare interactions, and healthcare practitioners, in addition to their patients, enter the healthcare encounter in terms of their own lived realities and a priori expectations and assumptions of how the world works, and this is the locus from which essentialism originates (Beck, 2001). She argues that "we tend to 'essentialize' types of others, often relying on categorizing people according to traditional categories of knowledge" (Beck, 2001, p. 219). Essentialism, according to Fuss (1989), can be understood as "a belief in the real, true essence of things, the invariable and fixed properties which define the 'whatness' of a given entity" (p. xi).



Cultural assumptions about women take on increased significance when considered in the context of a medical relationship because it is an encounter shaped by social and political factors including class, gender, and culture, just to name a few (Fisher and Groce, 1985; Navarro, 1976). Religious assumptions, gender role assumptions, and sex assumptions—the very assumptions that patient-centered communication and culturally competent communication frameworks attempt to alleviate—permeate each encounter and ultimately shape medical conversations and healthcare outcomes.

For example, in an effort to explore the efficacy of cultural competency training, Hunt and de Voogd (2005) conducted an ethnographic study of healthcare providers' perceptions of Hispanic/Latino culture within an amniocentesis decision-making context and found that the patients and providers had drastically different perceptions of test and treatment preferences. Hunt and de Voogd (2005) referred to this as an invocation of “clinical myths” about the Latino culture: the physicians described their Latina patients as likely to be “religious, fatalistic, male-dominated, family-centered, hold superstitions and folk beliefs, and harbor fears rooted in misunderstandings and hearsay” (p. 922); the Latina patients, on the other hand, accepted amniocentesis at a rate comparable to that of non-Latina populations and did not attribute birth anomalies to *brujeria*, *mal de ojo*, or other folk explanations. Hunt and de Voogd's (2005) study is an exemplar of what could happen when physicians have knowledge of patients' key cultural patterns and beliefs and use this knowledge in an incompetent manner. This is an example of ethnically essentializing patients, which is what happens when prevailing medical discourses about patients' cultural patterns end up becoming the “essence of a patient” within the medical

encounter at the expense of the patient's individual attitudes, beliefs, and actions (see Fleuriet, 2009). Instead of seeing a patient as a patient, some providers automatically categorize a patient's attitudes, beliefs, preferences and actions based upon her surname or medical chart. Instead of seeing a female patient as a female who needs some medical guidance or assistance, various identity categories are immediately laid upon the patient's identity slate. Research suggests that there is much within-group variation, such as Fleuriet's (2009) work, which explores the myriad approaches and experiences that characterize Mexican women's pregnancy-related social support. It can be concluded that within-group diversity "is one more piece of evidence that minority cultures cannot be essentialised in health disparities research" (Fleuriet, 2009, p. 57).

Furthermore, there is considerable variation in the terms *Hispanic*, *Latina*, *Mexican*, *Mexican-American*, *Tejana*, *Chicana*, *Mulata*, and *Indígena*? What's in a name? Although oftentimes patients are categorized as Hispanic/Latina, does identifying with a specific cultural/ethnic category shape and yield different health experiences? If so, to what extent? Scholars have begun to argue that academic discourses exploring Hispanic/Latino health experiences have both highlighted differences within this population and shown the variation within the categories *Hispanic* and *Latino* (Brown, Villarruel, Oakley, & Eribes, 2003; Sable, Havig, Schwartz, & Shaw, 2009), but more work needs to explore the nuances within these categories. Emergent within this body of scholarship is the notion that "ignoring these factors leads to significant problems in interpreting data and understanding the relationship of race, ethnicity and health among Hispanics/Latinos" (Amaro & Zambrana, 2000, p. 1724).

Thus, with this dissertation, I will explore Mexican-American women's pregnancy experiences, focusing on their perceptions of patient-provider communication and shared decision-making within the medical encounter and the impact of culture and gender politics on their pregnancy experiences, most particularly their acceptance, rejection, and negotiation of the amniocentesis procedure. Examining the construction of amniocentesis for Mexican-American women can illuminate the various controls of pregnancy and birth (Who chooses? The doctor, the spouse, and/or the pregnant woman?), as well as the various conceptualizations Mexican-American women have of "normality," "healthy," and disabilities (Rapp, 1994). Moreover, I also hope to shed some light on the relationship between identifying with a certain term/category and its influence on affecting and shaping women's pregnancy decision making.

This project is significant because it can show empirically how Mexican-American women experience their pregnancies, and it can also explicate the sexual, cultural, gendered and familial nuances that shape their experiences and decision-making. Moreover, it privileges women's voices about how cultural and gender roles and expectations shape and affect their pregnancies, not prevailing medical discourses that construct "the clinical and cultural other." Finally, it can improve women's medical encounters, as this research can explicate the cultural nuances located under the terms "Hispanic/Latino" (and any other cultural category my participants might identify with) and can inform existing culturally competent frameworks for healthcare professionals with a more intersectional approach to understanding and treating Hispanic/Latina

female patients. Now that I have considered the rationale for this topic, I turn to a review of the literature.

## CHAPTER II

### LITERATURE REVIEW

A conversation about prenatal screening and testing is a one that every pregnant female will likely have with her healthcare provider if she is in her thirties or above, and deciding to undergo prenatal testing is a complex decision. This chapter will discuss the various types of prenatal screening and testing, shared decision-making about prenatal testing, and more particularly, how one's ethnicity and culture can potentially complicate this process even further.

#### **Prenatal Testing**

Prenatal testing is a standard component of prenatal care in Western medicine, and the American College of Obstetrics and Gynecology (2007) recommends prenatal screening to all pregnant women, although it is emphasized more when women are 35 years of age or older (Browner et al., 2003; Griffiths & Kuppermann, 2008; Hunt et al., 2005). As I briefly mentioned above, the umbrella term “reproductive technologies” stands for a multitude of prenatal screenings and testing including but not limited to ultrasounds, blood tests, chorionic villus sampling, and amniocenteses. According to the American College of Obstetricians and Gynecologists (2014), prenatal screening tests and diagnostic tests are conducted for various reasons and at various stages during one's pregnancy. Whereas both screenings and testing are conducted to assess fetal risk and test for common birth defects, diagnostic tests are conducted to detect birth defects caused by genetic or chromosomal anomalies (American College of Obstetricians and Gynecologists, 2014). Diagnostic tests can also be conducted in place of screenings if a

couple already has a child with a birth defect, if a couple has a family history of a birth defect, if a couple is of a particular ethnicity that is most at risk for a particular birth defect, or if a woman is in her 30s or above because older age is associated with elevated risk for chromosomal abnormalities (American College of Obstetricians and Gynecologists, 2014; Rapp, 1994). Although prenatal screenings and testing are indeed optional, the American College of Obstetricians and Gynecologists (2014) recommends that women go through prenatal testing and screening because “knowing beforehand allows the option of deciding not to continue the pregnancy”.

The “Triple Screen” test mentioned above can only screen for birth defects. If a woman receives an abnormal screening test, a clinician typically discusses the test results with the pregnant woman in a genetic counseling session. According to Hunt, de Voogd, and Castaneda (2005), topics discussed in a genetic counseling session include the influence of heredity, the nature of the anomaly, and further testing options. Genetic counselors and clinicians who conduct the genetic counseling session intend to provide important medical information and provide emotional support to the pregnant woman as she decides whether or not she wants to go through “more definitive” testing, which is the amniocentesis procedure (Hunt, de Voogd, & Castaneda, 2005; Weil, 2003).

The amniocentesis is the prenatal test that is of most interest for this dissertation. Most typically encouraged for women who have positive genetic defect blood screenings and/or who are 35 years or older, the amniocentesis is a procedure in which a healthcare provider inserts a needle into the woman’s amniotic sac through her belly button to extract amniotic fluid and cells for examination. The amniocentesis procedure tests for

neural tube defects, genetic disorders, and various chromosomal abnormalities (American Pregnancy Association, 2014). Even though the amniocentesis procedure generally has high accuracy rates (98%; American Pregnancy Association, 2014), the test is associated with a variety of physical, moral, and ethical issues.

In terms of physical issues, potential amniocentesis side effects include leakage of amniotic fluid, infection, and a 1 in 200 miscarriage rate (Hunt, de Voogd, & Castaneda, 2005; Papantoniou et al., 2001). Moral and ethical issues associated with the amniocentesis procedure include what to do with the test results once they are received: “your child has spina bifida” or “your child has Down syndrome” are but two of the potential test results that a pregnant woman can receive, and there are no treatments for any of the conditions that can be found through the procedure (Hunt, de Voogd, & Castaneda, 2005). Amniocentesis test results often leave pregnant women with two options: life with a (possibly) disabled child or an abortion. This (very limited) choice is part of a growing debate in American culture about medical and maternal perceptions of what constitutes a “healthy, acceptable pregnancy” and thus a healthy, acceptable child (Katz Rothman, 1998; Rapp, 1994).

Feminist scholars have noted at length that reproductive technologies are riddled with a host of issues. Rayna Rapp (1994) discussed the advantages of prenatal testing, noting that it can reduce infant and maternal mortality and help patients and physicians alike work toward healthy pregnancy and birth outcomes. However, prenatal testing “controls conditions of pregnancy, birth, and parenting in ways that scientize our most fundamental experiences” (Rapp, 1994, p. 204). What used to be a pregnancy experience

free of scientific and technological intervention has transformed into a 9-month timespan full of prenatal testing procedures. Centered at the intersection of reproductive rights, disability rights, abortion rights, and the role of biomedical science (Rapp, 2000), the array of routinized and highly scientized reproductive technologies are deserving of their role in women's lived pregnancy realities, particularly the amniocentesis because of its role in keeping or terminating a pregnancy.

### **Shared Decision-Making and Prenatal Testing**

Considering the ethical and moral implications of prenatal testing and decisions that must be made after positive diagnoses (as they are so toxically labeled), informed and shared decision-making about prenatal testing has recently gained attention in the health practice and health policy spheres (Asch, 1999). However, before one can understand informed and shared decision making within this context, it is necessary to first describe the tenets of informed and shared decision-making.

Informed and shared decision-making (SDM) is a communicative task and process that draws upon notions of informed consent and informed choice, which has been defined by Charles et al. (1997) as “disclosure of treatment alternatives rather than merely informed consent” (p. 681). Charles et al. (1997) note that SDM has four main characteristics: (1) it involves at least two participants (the patient and the physician), (2) both parties take steps to participate in the decision-making process, (3) information sharing is a prerequisite to SDM, and (4) a treatment decision is made upon which both parties agree (pp. 685-688). Charles et al. (1999) elaborate upon this characterization by noting that in a SDM approach, each person needs to be willing to engage in the process



by both exchanging information *and* expressing treatment preferences, and that it should occur in a safe environment where the patient feels comfortable in exploring information and expressing opinions, ideas, and preferences. Ideally, if a patient and his/her physician engage in effective SDM, the high-quality decision should be one that, according to Epstein and Street (2007), is based on both the patient's values and understanding of the evidence and rationale for the decision. Thus, taken together, SDM is a process and social event between the patient and his/her provider that is characterized by trust, rapport, and active involvement and disclosure on behalf of all parties involved (Politi & Street, 2011).

However, SDM can become a complicated process when it involves the relationship between healthcare providers and pregnant women and the high-risk decision of undergoing prenatal testing. Bylund and Imes (2005) note that when considering SDM, it is important to consider the context within which the decision is being made. They argue that the medical context strongly impacts the nature and quality of the interaction, and the prenatal testing context is certainly an ethically- and morally-charged process that is characterized by high levels of stress, information seeking, information processing, and deliberation. Furthermore, Emery (2001) argues that SDM from a genetic counseling and testing perspective is “a different breed of informed decision-making” that complicates informed choice and SDM because (1) genetic test results have broader implications than non-genetic test results and may be perceived differently; (2) carrier status might be difficult for parents to conceptualize, particularly from a gender role perspective (which typically views males as strong, perfect, and

masculine, and females as weak, imperfect, and damaged); (3) genetic testing decisions are often multiple and sequential and are made at various levels that affect individuals and their families; and (4) most information is based on uncertainties and probabilities (p. 81). Thus, SDM about undergoing prenatal testing is a particularly delicate and tension-ridden encounter, and the process may not occur smoothly.

Many studies that have explored SDM within a prenatal testing context have found many factors that affect and shape the process, including women's attitudes toward and values about prenatal testing and abortion, prior knowledge about genetic testing, information needs, and patient-provider rapport. For example, Legare and colleagues (2011) surveyed patients and providers in Canada about their willingness to engage in SDM and found that both groups generally wished to engage in SDM about prenatal screening. The women's intentions to engage in SDM were enhanced when their physicians utilized decision aids to help them understand what prenatal testing entails. In another study conducted by Pivetti and Melotti (2012), results showed that three factors predicted a woman's intention to undergo prenatal testing: her need for more scientific information, a positive attitude toward genetic screening, and the inclination to terminate the pregnancy after receiving a positive test result (p. 1). Thus, women who favor science, are well educated about scientific testing, have high levels of family support, and have positive attitudes toward abortion are more likely to have a positive attitude toward prenatal testing, which makes the SDM process about prenatal testing much easier.

When women lack information or scientific knowledge about the prenatal testing process and what it entails, their involvement in the attempted SDM process could be hindered. Seror and Ville (2009) found that almost 70% of their participants viewed prenatal testing generally in a favorable manner, *but* a high proportion either were not aware of screening implications or did not understand them, e. g. half of them were unaware of the potential decision of terminating the pregnancy that could arise if results came back positive. There were also misunderstandings about what prenatal testing could do. Some women thought it could screen for all abnormalities and retardations, whereas other women thought that it could solve health issues, as well. Furthermore, most of the women who were unaware of or did not understand screening implications were passively involved in their decision-making with their physician, which Seror and Ville (2009) speculate could have been attributed to their lack of scientific knowledge about prenatal testing.

Downing (2005) found that decision-making is undoubtedly situated within a broader web of familial relationships and responsibilities, thus concluding that physicians need to be cognizant of family situations and relationships that might present additional stress for women within the SDM process. Oftentimes, the decision to undergo prenatal testing does not rest solely on the woman's shoulders; she might need to discuss it with her partner, her family members, co-workers, and perhaps even religious leaders before making a decision. Thus, physicians should be aware of the larger web within which a woman's decision is situated and the various influences that come into play, as these sources of information will affect the SDM process, as well.

Another interesting finding of Downing's (2005) study is that her participants' narratives revealed a variety of roles that were imposed upon their physicians and genetic counselors, thus advocating for physicians' awareness of the variety of roles they may need to play in the healthcare encounter (advocate for a particular strategy, supporter of the woman's choice, temporary family member, and moral authority). Thus, these studies paint a portrait of SDM within a prenatal testing context that some argue is more morally and ethically charged than other SDM contexts (say, for example, choosing between insulin injections or an insulin pump) and that requires physicians to become aware of all potential decision influences *and* physician roles. As such, it is no surprise that patients' cultural beliefs could complicate this process even more.

### **Mexican-American Cultural Dimensions**

The Mexican culture has unique cultural norms and gender relations. Thus, an exploration of Mexican cultural patterns and norms is necessary for one to understand and situate women's pregnancy experiences and negotiation of pregnancy decision-making with family members and healthcare providers.

Although there is much disagreement about what the category "Hispanic/Latino" actually means, there is much more agreement about the key cultural patterns and norms that occur in Mexican cultures and shape relationships, healthcare decision-making, and reproductive experiences. As many scholars note before undertaking an overview of cultural patterns and gender relationships, a disclaimer is warranted: this section is not meant to provide an essentialized construction of Mexican men and women; rather, it is meant to provide an overview of the construction of Mexican Latino cultural patterns

and gender norms that proliferate academic and medical discourses. This construction is necessary to provide a starting point from which to explore current cultural patterns, gender norms, and relational/decision negotiations as they play out in Hispanic/Latina pregnancy experiences.

Galanti (2003) argues that although the academic and medical discourses that construct “the Hispanic/Latino patient” sometimes stereotype it in the process, this information is actually meant to be a generalization. She notes that the difference between a stereotype and a generalization lies not in the *content* of the information, but rather in how the information is used. Thus, this section of the review—these cultural generalizations—is a beginning point, not an ending point, given that there is much variation within Hispanic/Latino cultures (Sable et al., 2009). This section focuses particularly on Mexican values and cultural factors, given that this segment of the population is of most interest for my study.

### **The Hispanic/Latino Family**

When one thinks of the traditional Mexican family, many familiar terms might come to mind: *familismo*, *personalismo*, and *machismo*, to name a few. These terms have been strongly supported by academic research over the past few decades. The family is the primary unit within Latino cultures and is a strong, if not the strongest, cultural value (Caballero, 2011; Galanti, 2003; Mendelson, 2002; Nuno, 1998). There is much reliance upon family members and the family structure, and as such, Mexican children frequently live at home until marriage, if not later (Galanti, 2003). Extended family members often share the nurturing, raising, and disciplining of children,

companionship for isolated or lonely members, and financial responsibility and problem solving (Falicov, 2005). It is evident that the strong family bond and high levels of reliance upon family members can create tensions within Westernized medical care, given that the biomedical approach privileges the individual as the primary healthcare decision-making unit (Caballero, 2011; Galanti, 2003). The basic Mexican family unit, which is larger than the traditional American nuclear family, includes aunts, uncles, cousins, godparents, and grandparents; this also has significant effects on the health decision-making process and treatment effects and outcomes (Caballero, 2011; Galanti, 2003; Page, 2003).

The notion of loyalty to both one's primary and extended family, even at the risk of the needs of the individual, is known as *familismo*. This concept places one's family and community relationships at the center of one's identity (Page, 2003) and is characterized by deep powerful bonds, loyalty, solidarity, and reciprocity within the immediate and extended family (Galanti, 2003). The notion of a "familial self" is a useful concept for making sense of *familismo* within Mexican families, as it suggests the internalization of family as an integral part of one's individual identity, thus contributing to family unity and family honor (Falicov, 2005; Roland, 1988). Traditional Mexicanos who privilege and enact *familismo* value familial interdependence, encouragement, cooperation, and advice, and sometimes include the entire family in the health process or even defer making a health-related decision to other family members (Caballero, 2011; Galanti, 2003; Page, 2003).

An extension of the importance of relationships that directly relates to one's relationship with a healthcare provider is *personalismo*, meaning intimate, personal relationships (Andrews & Herberg, 1999; Flores, 2000; Galanti, 2003). Caballero (2011) defines *personalismo* as "the expectation that a Hispanic/Latino individual will develop a personal relationship with their healthcare provider" (p. S12). This emphasizes a patient-provider relationship where the physician shows a genuine interest in and concern for the patient's life and acts as both a physician *and* a friend (Andrews & Herberg, 1999). Galanti (2003) builds upon this by noting that when physicians interact with Hispanic/Latino patients in a friendly and personal manner, they will be much more likely to trust physicians and confide in them, leading to stronger patient-provider relationships, increased compliance, and better health outcomes.

Another factor that could potentially influence Mexican women's interactions with their healthcare professionals are the notions of *religiosidad*, or religiosity and *fatalismo*, or fatalism. These two cultural values are closely related and reflect one's religious identification and perceptions of destiny. Religiosity, which declines with acculturation, is an incredibly important factor that shapes women's healthcare experiences and could lead to positive attitudes toward pregnancy and other health situations (Magana & Clark, 1995; Mendelson, 2002). Certain positive Mexican health behaviors such as refraining from drinking or smoking could be attributed to high levels of religiosity, such as reverence for the Virgin of Guadalupe as a role model and source of comfort and strength for Mexican-American women (Magana & Clark, 1995; Page, 2003). Overall, higher levels of *religiosidad* serve as a support system by providing

Hispanic/Latinos with the strength to cope with their diseases (Caballero, 2011), helps them remain positive and strong by facing their fears (Caballero, 2011), and predicts fewer negative health behaviors and more seeking of treatment for certain health issues (Gallo et al., 2009; Mann et al., 2007).

On the other hand, *fatalismo*, the belief that a person's destiny is beyond his or her control, can have both negative and positive health implications (Gallo et al., 2009; Cuellar et al., 1995). Fatalistic beliefs can sometimes function as barriers to disease prevention and early detection behaviors (Mann et al., 2007; Powe & Finnie, 2003; Schwab et al., 1994). However, scholars have also argued that the conceptualization of *fatalismo* as a health impediment is controversial (Abraido-Lanza et al., 2007) and that "efforts to disaggregate the construct are warranted in order to identify the underlying components of fatalism that may be most important to understanding Hispanics' utilization of health services and health care interventions" Gallo et al., 2009, p. 1724). This raises some questions, including: is *fatalismo* an important variable in Mexican-American women's reproductive decision-making processes? Do Mexican-American women refuse prenatal testing and an amniocentesis because God has already chosen their life path for them? How do they perceive their physicians' communication about these cultural values and topics?

### **Gender Politics in Hispanic/Latino Relationships**

Overall, research suggests that cultural values such as *familismo*, *personalismo*, and *religiosidad* can positively influence Mexican-American women's health outcomes. However, cultural concepts such as *machismo* and *marianismo*, which often govern



Hispanic/Latino intimate relationships and decision-making, can negatively affect both intimate relationships and Mexican-American women's agency within the medical encounter. Mexican relationships are oftentimes paternalistic and less collaborative, and this is largely due to how partners in the relationship perform the *machismo* and *marianismo* gender roles.

*Machismo*, the male gender performance, can have both positive and negative associations. According to Galanti (2003), positive aspects of *machismo* include the pride of men to "behave valiantly to protect the honor and welfare of their families" (p. 183) and to provide for their family and live up to their male responsibilities. *Machismo*, on one hand, is a strong work ethic and a man's dedication to his children and family's well being (Falicov, 2005). On the other hand, the dark side of *machismo* can be defined as "a strong or exaggerated sense of masculinity stressing attributes such as physical courage, virility, domination of women, and aggressiveness" (Miranda, Bilot, Peluso, Berman, & Van Meek, 2006, p. 270). This aspect of *machismo* is a gender performance characterized by patriarchal dominance and authority (Gallo et al., 2009). Moreover, the dark side of *machismo* can contribute to negative health behaviors such as promiscuity, unprotected sex, spousal abuse, aversion to contraceptives, and family conflict (Galanti, 2003; Gallo, 2009; Tamez, 1981). *Marianismo*, the Mexican female gender role counterpart, is characterized by female passivity, dependence, and self-sacrifice (Gallo, 2009; Stevens, 1973). Mexican women who perform the *marianismo* role often place their family needs first, at the expense of their own health, and this unequal relationship often privileges the male partner's wants, needs, health beliefs, and health preferences.

Within this relationship, mothers may make minor day-to-day decisions, but the husband is to be consulted with major important decisions, including those regarding the women's health (Galanti, 2003).

Gallo and colleagues (2009) argue that the extent to which *machismo* and *marianismo* are associated with health outcomes is not well understood, and other scholars have shown that *machismo* could potentially be an outdated and less frequently practiced gender norm in Mexican relationships and reproductive health (Gonzalez et al., 2010). Research, however, is conflicted at best. Harvey and colleagues (2002) interviewed 39 Mexican couples and found that the men in the relationship reported that they felt powerful when they had control over their female partners and could command them. This control and subservience consisted of keeping the woman silent, not letting her express what she wanted, giving up her will, and appearing weak and submissive. In terms of decision-making about sexual and reproductive matters, however, almost all of the participants agreed that these decisions were made by both relational partners, leading the authors to conclude in accordance with Browner (2000) that women are neither "agents acting solely on their own free will or completely constrained by the actions of men" (p. 290).

Gonzalez and colleagues (2010), on the other hand, interviewed 100 second-generation Hispanic men and women and found that exploitative reproductive behaviors did not occur in their relationships. They note that they found "no patriarchal ideology supporting women's subordination to men, violence as a mechanism of control, reproduction as a way of exploitation, or cultural influences discouraging access to and

use of birth control in the Hispanic community” (p. 551). This population had adequate knowledge of contraceptive use and more egalitarian gender roles, and additional research confirms that second-generation Mexican-American women are becoming more liberated from the patriarchal ideologies that might have constrained their mothers’ and grandmothers’ relationships and reproductive decision making (Blea, 1997). Is the conceptualization of Mexican-American families as rigidly patriarchal becoming more of a stereotype and less of an actual cultural phenomenon? Do Mexican-American women have adequate knowledge of prenatal testing and amniocenteses, as well as more egalitarian relationships with their partners? This dissertation plans to contribute to understanding the nuances of how these cultural and gender roles are performed within Hispanic/Latino relationships and how this affects reproductive decision-making.

### **Hispanic, Chicana, Latina, Tejana, Indígena, Mestiza, Raza: What’s in a Name?**

#### **“Utter Confusion”**

While there is an overall consensus of what constitutes Mexican cultural norms and gender roles, scholars are conflicted about what the identity category “Hispanic/Latino” means and how this category contributes to health research and affects health outcomes. Broadly, a person’s ethnicity can both directly and indirectly affect health outcomes by influencing health beliefs, the manner of expressing symptoms and pain, the access one has to healthcare systems, and one’s treatment preferences (Atkinson, Casas, & Abreu, 1992; Ford & Kelly, 2005; Marin, Gamba, & Marin, 1992; Williams & Jackson, 2000). Identifying a patient’s ethnicity has been routinely integrated into healthcare encounters because it can help physicians understand, even if

at least at a very base level, their patients' explanatory models, treatment preferences, and treatment responses (Ford & Kelly, 2005). Moreover, ethnic patterns and beliefs have also been integrated into cultural competence models and curricula because culturally competent healthcare could improve health outcomes and drastically reduce health disparities (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003; Betancourt, Green, Carrillo, & Park, 2005):

A "culturally competent" health care system has been defined as one that acknowledges and incorporates—at all levels—the importance of culture, assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally unique needs. [It] is also built on an awareness of the integration and interaction of health beliefs and behaviors, disease prevalence and incidence, and treatment outcomes for different patient populations.

(Betancourt et al., 2003, p. 294).

Thus, a patient's cultural identification/ethnicity is an incredibly important component of the healthcare encounter. While it is widely agreed upon that healthcare providers must understand the population they are seeking to help to provide the best care possible (Santiago, 1993), research suggests that this identity category, the "elusive 'Hispanic/Latino' population", and the ways in which it manifests within healthcare encounters is flawed at best (Hayes-Bautista, 1983, p. 274). What is the Hispanic/Latino culture? What is a Hispanic/Latino patient? Furthermore, what is the relationship between a Hispanic/Latino patient's culture and his/her healthcare practices and beliefs?

## **The Category “Hispanic”**

Although it is outside the scope of this dissertation to provide a complete historical and political overview of the evolution of the terms “Hispanic” and “Latino,” this section is intended to provide a brief overview of the categories that can provide a platform for an exploration of the ways in which one’s cultural/ethnic identity contributes to and shapes health experiences and decision-making. The Hispanic/Latino/Raza population is very heterogeneous, ranging from the “non-Spanish-speaking Indians of rural Mexico to British-descended Argentines or Germanic Chileans” (Hayes-Bautista, 1983, p. 274). Moreover, although the terms “Hispanic” and “Latino” are often utilized together within public health research and cultural competence healthcare curricula and programs, the two terms are actually very different. The “Hispanic” category was created in the 1970s by the federal Office of Management and Budget (OMB). It was first operationalized as “a person of Mexican, Puerto Rican, Cuban, Central or South America or other Spanish culture or origin, regardless of race” (Hayes-Bautista & Chapa; 1987, p. 64). Although at first glance this definition seems to provide a fairly straightforward conceptualization of a Hispanic person’s cultural/ethnic background, “epistemologically, this definition is a mixture of a culturally derived term (Hispanic) partially operationalized by nationality, partially by culture, and partially not operationalized at all by the extremely open-ended phrase ‘other Spanish origin’” (Hayes-Bautista & Chapa; 1987, p. 64). Moreover, the OMB’s definition “largely focuses on the countries of origin and assumes that people in those countries have a common ‘Spanish culture,’ which is also shared by some people living in the United

States” (Castex, 1994, p. 289). But what is this common Spanish culture that we all supposedly share?

The term “Hispanic” has cultural connotations, as opposed to ethnic connotations (Poma, 1983), and refers to “people born in a country conquered by Spaniards and for whom Spanish is the primary language.” Poma (1983) elaborates upon this point by noting that due to “multiple interracial unions throughout the centuries, predominant ethnic characteristics are lacking among Hispanics. Their ethnic backgrounds are mixed” (p. 941). Taking a more critical approach, Yankauer (1987) argues that, at a broader level, oftentimes Hispanics are “lumped together as a single group without even the dignity of being assigned to a country of origin” (p.15).

Scientific literature on healthcare and ethnic/cultural categories has established five distinct categories of Hispanic subgroups: Mexican Americans, Cuban Americans, Puerto Ricans, Central or South Americans, and “other” (Santiago, 1993). As a result of various immigration histories, these subgroups are distinctively distributed across the United States: Mexican Americans, who comprise 63% of the country’s Hispanic population, reside mostly in California and Texas; Puerto Ricans, comprising 13% of the country’s Hispanic population, are concentrated mostly in New York; Cubans, who comprise 11%, can be found mostly in Florida; and other subgroups residing in New Mexico and Chicago (Santiago, 1993). However, a few glaring limitations of this categorization include the fact that the broad geographic distribution renders healthcare generalizations useless (Santiago, 1993), and Hispanics are often very individualistic, due to regional differences and other factors (Poma, 1983).

## **The Category “Latino”**

Whereas the term “Hispanic” has specifically cultural connotations, the term “Latino” is more inclusive, referring to “people born in a country whose language evolved from Latin (the romance languages)” (Caballero, 2011, p. S10). Hayes-Bautista and Chapa (1987) elaborate upon this definition by noting that the term “Latino” derives from Latin America, is culturally and racially neutral, is more generic, and “preserves the flavor of national origin and political relationship between the U.S. and Latin America” (p. 65). In addition to this term being more “neutral,” certain scholars have argued that “Latino” is the term that is *least* objectionable because “a major trait shared by all Latin American countries is not language, race, or culture, but is political” (Hayes-Bautista & Chapa, 1987, p. 67). Thus, it has been argued that “Latino” is the most appropriate term to use for persons residing in the U.S. of Latin American origin because it reflects nationality, not language or culture (Hayes-Bautista & Chapa, 1987).

## **The “Hispanic”/“Latino” Debate**

However, this perspective is only one side of the debate. Regarding terminology and identity categories, most defenders and critics agree that a “standardized terminology” is necessary to identify factors such as the groups’ needs, health issues, and access to health services, and those who support utilizing the term “Latino” argue that the term “Hispanic” has racist implications due to its roots in the history of U.S. political and economic domination over Latin America (Gimenez, 1989; Hayes-Bautista, 1980; Hayes-Bautista & Chapa, 1987). Those who defend utilizing the term “Hispanic” argue that it is a better term on “scientific, political, and pragmatic grounds” because

federal and government agencies use this term, thus creating more ease in relating population, health, and epidemiological statistics; because a new term would create too much confusion, because it is important to have comparable data; and because the term is rife with political discrimination (Gimenez, 1989, p. 558; Hayes-Bautista, 1983).

While it is evident that both the “Hispanic” and “Latino” categories have both advantages and disadvantages, some scholars argue that the terms should be eliminated altogether. These scholars note that the terms are problematic for two main reasons: (1) the “label does not help either social scientists or policy makers because it only creates an artificial population, i.e. a statistical construct formed by aggregates of people who differ *greatly* in terms of national origin, language, race, time of arrival in the United States, culture, minority status, social class, and socioeconomic status” (Gimenez, 1989, p. 559); and (2) attempts to account for cultural variation rests ultimately upon cultural generalizations and stereotypes. Supporting the first reason, Santiago (1993) argues that the fact that “no term has [been] met with everyone’s approval is indicative of the diversity of the Hispanic population. [We] need to accept the lack of a single descriptive term and effectively address the many pressing needs of this rapidly growing minority” (p. 613). Supporting the second reason, Gimenez (1989) argues that the term “Hispanic” is an insufficient and inappropriate term because it has “created an irresolvable tension between political and research needs that, in the long run, will result in ineffective policies and the accumulation of data of doubtful significance” (p. 568). This irresolvable tension not only results in ineffective policies and data, but also manifests itself in other areas:



Regardless of politicians' concerns for numbers, social scientists and policy makers must seriously confront the problems attached to this and any other umbrella term: the stereotyping and minoritization of foreigners; the transformation of minority groups into mere statistical categories, thus subverting the historical reasons for their situation and their claims upon the resources of the state; the creation of a synthetic or artificial "ethnicity"; the production of data difficult to interpret in nonracist or stereotypical fashion, and so on. (Gimenez, 1989, p. 569).

Due to these negative outcomes, scholars such as Gimenez (1989) Santiago (1993) argue that the terms should be eliminated altogether. Gimenez (1989) posits that, in addition to acknowledging the qualitative differences in one's history, culture, class, and social stratifications, the "Hispanic/Latino" population should be separated into two main minority groups—people of Mexican and Puerto Rican descent—and four additional aggregates consisting of Cubans, Central Americans, and South Americans because this categorization is less laden with racism and stereotypes due to national identification as opposed to ethnic identification. Although this new categorization never quite made it past certain academic circles, it is still exemplary of the extreme division located inherently within whether to have a "unifying umbrella term" for the Hispanic/Latino population and of how, two decades later, I would argue still exists.

Thus, given the advantages and disadvantages of utilizing a "unifying umbrella term" (Hispanic? Latino? Raza?) and the various definitions that have been used, for this study, I am defining the Hispanic/Latino population in accordance with the U.S. Census.

According to Ennis, Rios-Vargas, and Albert (2011), the Hispanic/Latino population was defined as “a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race” (p. 2) (see Appendix 1 for table of the categorization of nationalities). Although I will use the Hispanic/Latino umbrella term and I plan on interviewing second- and third-generation Mexican and Mexican American women, in an effort to not impose my terminology and categorization upon my participants’ identities, I plan to ask them what the terms “Hispanic” and “Latino” mean to them and, if these terms are not relevant to their identities, what terms *do* they use for their ethnic/cultural identification? Is it a negotiation between and among “Hispanic,” “Latino,” “Chicano,” “Tejana,” and/or “Raza”?

Yankauer (1987), in discussing the need for a conglomerate term, muses, “Why choose ‘Hispanic’? I do not know the answer to this question. No one has taken the trouble to poll the group to be identified and asked them what they would like to be called” (p. 16). Moreover, he argues that what our society needs to do is garner a “truly representative opinion poll of those of Latin American descent or origin. We need to know not only what they prefer to be called, but also how they would designate themselves under a variety of different questions” (p. 17). While I cannot garner a truly representative opinion poll in this dissertation, I *can* attempt to figure out what these identity categories mean to my participants and how this meaning shapes, constructs, and affects their reproductive decision making. As Hayes-Bautista (1983) notes, “The heterogeneity of the Raza population must be taken into account, or plans and policies may miss the mark widely” (p. 276).

## **The Role of Hispanic/Latino Cultural Dimensions in the Prenatal Testing SDM**

### **Context: “Juxtaposing Role Enactments & Knowledge Bases”**

Thus, it is evident that a multitude of cultural dimensions, family obligations, relational gender norms, and identifications converge and form a complicated space within which Hispanic/Latina women experience their pregnancies and make decisions about their prenatal care, prenatal testing, and amniocentesis preferences. Many studies have explored the role of culture in women’s decision-making processes about prenatal testing with genetic counselors and other healthcare providers. For the purposes of this study, this section will focus specifically on four dimensions as they relate to the prenatal testing decision-making process: religion, race/ethnicity, knowledge and information about the testing process, and patient-provider communication issues.

The first dimension, religion, has garnered conflicting results about its role in Mexican-American women’s perceptions of and decisions regarding prenatal testing. Although one might hypothesize that Mexican-American women would be overwhelmingly Catholic and would decline prenatal testing and amniocentesis at higher rates than non-Mexican women, the small research that has explored this dimension has found that the role of religion is very flexible. Seth and colleagues (2011) evaluated the role of religion and spirituality as it relates to Latina women’s prenatal diagnosis decisions and found that religious/spiritual beliefs were indeed important and provided comfort to the women as they dealt with the process, yet the risk of procedure-related complications played a more concrete role in the decision-making process than their beliefs did. Similarly, Atkin and colleagues (2008) found that women’s decisions to

undergo prenatal testing were generally related to their attitudes toward abortion and were mediated by religious and faith beliefs. While religion was an important variable in this study, what was most important was the woman's faith—"faith beliefs emerged as flexible, negotiable, and contingent: a resource, which could be used creatively to support and legitimate a person's decision" (Atkin et al., 2008, p. 29).

Rapp (2000), in her ethnography of women's experiences with prenatal testing, discusses how minority women (African-American and Hispanic/Latina [Puerto Rican and Dominican], particularly) are less likely than white women to undergo prenatal testing for reasons including but not limited to lack of knowledge about and uncertainty of the process and what it entails, beliefs that life is sacred and that God will take care of them and their child, and partner opposition to invasive testing and the possibility of an abortion procedure. These values and beliefs were sites of negotiation and contestation between women and their genetic counselors as they explored whether or not to undergo prenatal testing, and this provides an additional perspective to the notion that religion is a flexible and negotiable resource in this complex process.

The second important dimension surrounding this context is race/ethnicity. Research suggests that race/ethnicity factor negatively into the SDM context about prenatal testing because current debates and discussions about the role of race/ethnicity within this context "are not neutral but evoke a specific set of received ideas and codes of intervention, embodying social and power relationships" (Atkin, 2003, p. 91). Furthermore, Atkin (2003) argues that the counseling that occurs when genetic counselors and other healthcare providers try to engage in SDM with minority patients

sometimes uses the term “informed choice” as a cover-up for “the right decision” of aborting genetically inferior fetuses—but what is the right decision? According to whom? Additional research suggests that minority women are especially marginalized when it comes to prenatal testing because their knowledge of what prenatal testing entails is often low, significant language barriers may exist, information exchange and processing may take place across “cultural and linguistic divides,” and some physicians might be influenced by institutional racism and unacknowledged negative stereotypes toward minorities (Anionwu & Atkin, 2001; Atkin, 2003, Firduous & Bhopal, 1989).

The third dimension is the role of knowledge and information about the prenatal testing process. Research that has explored Hispanic/Latinas’ experiences with SDM about undergoing prenatal testing has found daunting results. As was mentioned earlier, having adequate knowledge and information about the decision at hand and what the technological process entails is absolutely necessary before a patient can have a well-informed, empowered discussion with her physician and before the two parties can come together to make a decision. Research suggests that Hispanic/Latinas are less knowledgeable about genetic testing than whites and often have many misperceptions about the genetic testing process and what genetic testing actually assesses (Griffiths & Kupperman, 2008; Penchaszadeh & Punales-Morejon, 1998; Singer et al., 2004; Suther & Kiros, 2009). Griffiths & Kupperman (2008) examined rural Latinas’ understanding of prenatal testing and risks and found that they were overwhelmingly supportive of prenatal care because it assesses the fetus’ health, *but* they had many misperceptions

about prenatal testing, including the fact that a normal screening result automatically guarantees a fetus' good health.

Similarly, Penchaszadeh and Punaless-Morejon (1998) surveyed 100 Latino patients prior to genetic testing and found alarming results: (1) two-thirds believed incorrectly that prenatal testing could detect all genetic diseases and mental retardation and that it could predict the overall health of the fetus; (2) less than 40% knew what prenatal testing actually screens for; (3) 31% reported undergoing prenatal testing at their physicians' insistence; (4) 63% refused prenatal testing because of fear of miscarriage; and (5) 30% stated that abortion would not be an option because of moral and religious beliefs. This lack of information and acquisition of incorrect information has the potential to negatively affect shared decision-making because women might be making potentially life-changing decisions on a faulty information base.

The fourth and final important dimension surrounding the prenatal testing decision-making context is patient-provider communication barriers and issues and culturally (in)competent healthcare. In addition to the lack of adequate knowledge that Hispanic/Latinas' have about prenatal testing, communicative misguidings and errors also characterize prenatal testing decision making between Hispanic/Latinas and their physicians. Language barriers complicate the communicative process, both when physicians use excessive medical jargon and when translator-patient-provider communication processes hinder comprehension of genetic information and development of patient-provider trust (Browner et al., 2003; Browner & Preloran, 2004). SDM is also hindered because Latinas often report skepticism about prenatal testing and

often do not disclose their perceptions and beliefs to their healthcare provider (Browner et al., 2003). This lack of disclosure in certain cases shuts down communication, thus sending incorrect verbal and nonverbal signals to the physician (Browner & Preloran, 2004).

Another communication issue that arises frequently within this context is that of culturally (in)competent healthcare. Research exploring cultural competence successes and failures in the prenatal testing decision-making realm have found conflicting results: either physicians severely lack cultural competence in healthcare encounters or they overcompensate what they think are culturally competent actions (which was a surprising finding), both of which result in patients who feel stereotyped and are dissatisfied. On the lacking end of the spectrum, as was mentioned earlier, Hunt and de Voogd (2005) surveyed both clinicians and Latina patients who discussed prenatal testing and found alarming results: the physicians overwhelmingly invoked “clinical myths about the cultural other” by noting that Latinas are more likely to decline prenatal testing because they are “religious, fatalistic, male-dominated, family-centered, and superstitious,” whereas the Latina patients accepted prenatal testing at a rate comparable to whites and did not fit into the cultural pigeonhole created by their physicians. Furthermore, in this study, clinicians provided less information about prenatal testing to their patients because they thought it was a “culturally sensitive maneuver” (Hunt & de Voogd, 2005); providing less information, according to the physicians, was a good idea because then they would not offend their patients or tread problematic ground. Thus, it is evident that following a cultural competence cookbook approach when dealing with

minority patients can backfire because it can detrimentally affect the consultation and the patient-provider relationship. If providers are refusing to provide information about prenatal testing to their patients, they are dooming shared decision-making from the start.

On the other end of the cultural competence spectrum, Browner and colleagues (2003) found that one of the major communication breakdowns between physicians and Latinas when discussing prenatal testing was the fact that physicians “misplaced cultural sensitivity” and had an *excess* of cultural sensitivity (or what they thought was culturally sensitive, at least). Browner et al. (2003) argue that physicians need to be culturally sensitive, but excess cultural sensitivity interferes with open and direct communication (p. 1939). They stated that, “counselors are wary of addressing the mistaken beliefs of their clients when those misapprehensions appear to be rooted in the client’s ethnic or cultural background” (Browner et al., 2003, p. 1939). Clinicians actively avoided giving information about prenatal testing and discussing women’s ethnic beliefs because they did not want to offend the patient and jeopardize rapport. Browner et al. (2003) argue that avoiding discussion of the aforementioned issues creates a serious communication gap, which has detrimental effects on SDM and the choices the women will make in the future.

Thus, deciding whether or not to undergo prenatal testing is one of the most difficult decisions a woman can make during her pregnancy. Research has suggested that engaging in effective shared decision-making about prenatal testing can help the patient become more educated and more empowered, thus leading to a satisfactory decision that



is rooted in the patient's beliefs and values. A woman's cultural upbringing, norms, and resources complicate this delicate process, and this becomes more apparent when exploring Latinas' experiences with trying to engage in shared decision-making about prenatal testing with their providers. Although Latinas generally look upon shared decision-making favorably, they are often working with faulty information bases and are stereotyped by their physicians, which dooms the SDM process from the very beginning. Physicians need to use cultural characteristics and patterns as a starting point, not the end point, and they need to ask their Hispanic/Latina patients what their thoughts, beliefs, and attitudes are about prenatal testing, as opposed to conducting the medical encounter with faulty assumptions.

This is where my dissertation enters the conversation: multiple factors converge to create a prenatal care/testing decision-making encounter situated within cultural patterns, gender norms, and both patient and provider knowledge and power, and it entails knowing and negotiating how much information both parties should disclose (preferences, scientific facts, ideas, values, attitudes, fears, etc.), when to give it, and how to deliver it (Gillotti, 2003). Bylund and Imes (2005) argue that three main factors should be considered when trying to understand the decision-making process: the context in which the decision occurs, the physician-patient relational context of the decision, and the patient's personal context for making the decision. Moreover, they note how all of these factors converge:

Each patient has a unique personal context; he or she is embedded in multiple systems, such as families, friends, cultures, organizations, and societies. Within

each of these systems, health communication occurs that affects and is affected by the physician-patient talk. All of these contexts can have important implications on the shared decision-making process. (Bylund & Imes, 2005, p. 69)

Thus, this dissertation will explore physician-patient talk about prenatal testing and amniocentesis from the perspectives of Mexican-American second- and third-generation women. As was mentioned earlier, little research has explored Mexican-American women's shared decision-making experiences with their physicians and their perceptions of their providers' communication. The research that *has* been conducted shows that Hispanic/Latina women report misperceptions about and lack of information regarding prenatal testing; are hindered by language barriers; are stereotyped and essentialized by their physicians, resulting in physicians not even offering certain prenatal tests and options; and often include their family members and religious values as factors that shape their decision (Rapp, 2000). But what about Mexican-American women's perceptions of how their cultural and gender norms affect this process? Do they have to make decisions about reproductive testing first with their spouses/partners *and then* with their physicians? Or do cultural and gender norms take a backseat in the decision-making process, whereas physician communication styles come to the fore? How does being a second- or third-generation Mexican-American woman change, shape, or affect one's experiences, as opposed to being a first-generation immigrant? Thus, this dissertation is guided by three main research questions:

- 1) What are Mexican-American women's experiences of making decisions about prenatal testing and getting an amniocentesis with family members?
- 2) What are Mexican-American women's perceptions of their healthcare professionals' communication about prenatal testing?
- 3) What is the relationship between Mexican-American women's identities, generational status, and decision-making about prenatal testing and amniocentesis?

My goal for this dissertation is to understand the cultural, gendered, religious, and familial nuances that shape Mexican-American women's prenatal testing and amniocentesis decisions in order to contribute to academic and medical discourses that both construct Hispanic/Latino cultural norms and values and examine how these norms and values contribute to health outcomes, as well as to inform future culturally competent communication frameworks to help physicians and Hispanic/Latina patients have more efficient, more collaborative, and more smooth decision-making processes and experiences. Now that I have reviewed the literature, I will discuss my methodology for this study.

### CHAPTER III

#### RESEARCH METHODOLOGY

As a self-identified Tejana feminist (third generation on my father's side and fifth generation on my mother's side) who is working hard in adulthood to perfect my ability to speak my Tex-Mex Spanish (Anzaldúa, 2012), I have always been interested in how Hispanic/Latino cultural patterns and norms influence and guide one's health beliefs, as well as how health beliefs and behaviors ebb, flow, and wane depending upon how long one has been living in America. One exemplar of this research interest takes me back to a time when I was five years old and suffering from a very high fever and sore throat. My mother, a strongly self-identified Tejana who identifies more with her Spanish roots than her Mexican roots and is also a firm believer in biomedical care, argued that I needed to be taken to the hospital, lest the fever turn into something much worse. My maternal grandmother, on the other hand, who lived with us the first 21 years of my life and was a strong believer in cultural and alternative forms of healing, insisted that cleansing me with a blessed egg and salt would cure my fever. After about an hour of heated discussion, my grandmother won that argument and proceeded to clean me with an egg. She prayed over the egg, put it in a bag of salt, and then ran the egg over me from head to toe, praying the rosary and praying for the egg to take my sickness. When she was finished, she cracked the egg and threw it away. The next morning, I felt a lot better and didn't have to go to the hospital after all.

This childhood experience is not about reproduction and decision-making about prenatal care, yet it *does* illuminate how one might negotiate cultural beliefs and health

practices with one's faith in biomedical care. My mother notes that she prefers biomedical care as opposed to older cultural healing traditions because "it's proven, it works," whereas my grandmother continues to use older cultural healing traditions because "it's part of who I am, it's what I know, and I believe it works." This negotiation of "old-world" and "new-world" faiths in healing practices and health behaviors is initially what sparked my interest in this topic. In the spirit of self-reflexivity (Lindlof & Taylor, 2011; Tracy, 2013) and exploring my subjectivity as it relates to my study, I am aware that being a third-generation/fifth-generation Hispanic female will influence my interactions with participants and my analysis of the data. I directly attribute my lack of identification with older cultural healing traditions to my generational status because the older health traditions have been lost through translation to me throughout the years. I identify more with Westernized healthcare and would perhaps trust my physician to heal me more so than an egg cleansing, whereas I identify less with older Mexican healing traditions and even less with older Spanish healing traditions. Thus, one central goal of this dissertation is exploring my participants' perceptions of how and to what extent their generational status shapes and affects their health beliefs and practices within a prenatal care/amniocentesis context.

The second central goal of this dissertation comes from my perceptions of and qualms with the treatment of Hispanic/Latino populations within the Western medical system. As I mentioned in the literature review, clinicians frequently essentialize and stereotype their Hispanic/Latina patients, particularly within sexual and reproductive health contexts. I, too, have experienced this phenomenon. During one routine visit with

my gynecologist, I asked her about various birth control methods and their side effects, and she responded by saying, “Oh, why are you interested? I thought you were Catholic and that Catholic women don’t take birth control.” Oh, the irony of simultaneously researching a given phenomenon and actually being at the center of this phenomenon as it plays out and affects you. Thus, in addition to exploring generational effects on health decisions and practices, I am also interested in exploring my participants’ perceptions of their clinicians’ communication skills, particularly the role of religion and relational gender politics as they relate to making a complicated decision about prenatal testing and amniocentesis. To understand this phenomenon, I conducted a qualitative study and utilized in-depth, semi-structured interviews; however, before I discuss my methodology, I must first discuss why I chose qualitative methods for this dissertation.

### **Why Qualitative Methods? Which Qualitative Methods?**

I used qualitative methods because qualitative research allows researchers to explore human understanding, lived experience, and the nuances and negotiations that people experience in their everyday lives as they navigate the healthcare system and make important decisions about their health. It can also help unpack the processes surrounding healthcare communication and explore what “really” is going on (Britten, 2011, p. 388). Moreover, qualitative research is a useful tool for understanding societal issues that arise from cultural contexts (Covarrubias, 2002; Kreuter & McClure, 2004; Tracy, 2013). Issues such as ethnicity, gender, race, and sexual orientation can be understood, critiqued, and transformed through contextual studies that examine how

these demographic categories are negotiated, ever-changing, and communicatively constituted (Tracy, 2013).

In order to understand my participants' emergent and collaborative social realities, I conducted semi-structured, in-depth interviews with participants. In-depth interviews allowed me the ability to explore my participants' views of reality (Reinharz, 1992) and support or disconfirm already existing statistics and generalizations (Sexton, 1982) about Mexican-American women's perceptions of decision-making with spouses and clinicians about prenatal testing and amniocentesis. Moreover, in-depth interviews allowed me to elicit the language used by my participants to describe their experiences, garner their stories and explanations, and perhaps lead me to new interview questions and phenomena that I had not previously considered (Lindlof & Taylor, 2010).

### **The Research Participants**

After receiving IRB approval, I interviewed first-, second- and third-generation Mexican-American women between the ages of 30-45 who had at least one pregnancy and live in Houston or San Diego because I wanted to explore Hispanic/Latino within-group variation and conduct a comparative analysis of their experiences.<sup>2</sup> I specifically chose this population much research has already explored how immigrant Mexican women experience their pregnancies and deal with the tensions of negotiating birth

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<sup>2</sup> Although I originally intended upon interviewing only second- and third-generation Mexican-American women, I realized in the midst of conducting interviews that accurately pinpointing participants' generational status proved to be a daunting task. Like me, many participants had parents with varying generational statuses, so I categorized their generational status according to their how they identified, not traditional definitions of first-, second-, and third-generation Mexican-American women.

practices in Mexico and losing family ties, family traditions, and family support while making prenatal testing-related decisions and giving birth here in the U.S. (Galvez, 2011; Gutierrez, 2008). No research has explored second- and third-generation Mexican-American women's negotiations of reconciling and making sense of their birth practices, beliefs, and traditions back in Mexico, particularly within a prenatal care/amniocentesis context, and the birth practices, beliefs, and customs they have experienced and perhaps adopted as they have lived here in the U.S. Given that the Hispanic/Latino population is booming here in the U.S. and that this population is projected to soon become the majority, knowledge of Mexican-American women's experiences of making decisions with spouses and clinicians can help inform future genetic counseling and cultural competence curricula, as well as improve future healthcare encounters that deal with this complex decision-making process.

Approximately 15 women were interviewed in Houston, and 15 women were interviewed in San Diego. I utilized the snowball sample recruitment method, meaning my key informant in each city helped me recruit participants by suggesting friends, family members, and co-workers. Participants suggested women in their social networks as well, and I was able to conduct all of the interviews in each city within a one-month time span. Interviews with participants lasted on average one hour and were mostly conducted at local coffee shops.

Some of the overarching questions I had in mind while conducting my interviews included: Do Mexican-American women in Houston have similar or different shared decision-making experiences as compared to those in San Diego? What can we learn



about Mexican-American cultural nuances, particularly religiosity and relational gender politics, as they pertain to women making decisions about prenatal testing? An exploration of these cultural nuances can help illuminate the existence (or not) of regional gender politics, religiosities, and health beliefs as they pertain to making prenatal care decisions (Gonzalez-Lopez, 2004; Sangari, 1995) and contests the notion of a uniform Mexican gender politic and religiosity as they pertain to one's health.

### **Data Analysis: Thematic Analysis**

Since I gathered 30 respondent interviews (Lindlof & Taylor, 2010), I conducted a thematic analysis to explore the various themes, categories, and codes that emerged from the data and from my participants' experiences. According to Boyatzis (1998), thematic analysis is, in its most basic sense, a way of seeing. More specifically, Braun and Clarke (2006) claim it is "a method for identifying, analyzing and reporting patterns (themes) within data" (p. 79). Thus, I created categories and a coding scheme based on patterns, similarities, and notable exceptions in the data (Lindlof & Taylor, 2010). I first identified categories pertaining to gender politics, religiosity, identity, and shared decision-making, which were then collapsed into themes and their corresponding categories.

I also wrote two reflexivity journals as I conducted my interviews. Reflexivity journals are important research tools because they support the credibility of a scholar's arguments, in addition to the dependability, transferability, and confirmability of one's study (Erlandson, Harris, Skipper, & Allen, 1993). Reflexivity journals serve as a diary for the investigator in which s/he records information such as research schedules and

logistics, insights, reasons for methodological decisions, and initial thoughts and analyses (Lincoln & Guba, 1985). Not only will my reflexivity journals serve as an audit trail for my analysis, but they will also serve as a place for me to explore not only my participants' identities, health, and perceptions, but mine, as well.

## CHAPTER IV

### QUIÉN ES LA MUJER MEXICANA? MEXICANA AND CHICANA IDENTITY

For most of us, our ethnicity is still the issue.  
Ours continues to be a struggle of identity—  
not against a white background so much as against  
a colored background.

~Gloria Anzaldúa (1987/2009), p. 115

Who is the Mexican woman? This is a question that lies at the heart of Chicana/o studies and Chicana feminist scholarship. For the past century, scholars in disciplines such as Chicana feminist studies (Anzaldúa, 2012; Castillo, 1994; Keating, 2009; Moraga, 2011; Moraga & Anzaldúa, 1983) and communication studies (Calafell, 2004; Calafell & Delgado, 2004; Calafell, 2005; Flores, 1996; Holling, 2006; Holling & Calafell, 2011; Martinez, 2000) have sought to explore discursive, performative, and embodied constructions of what it means to be a Mexican-American/Chicana female in the U.S. during the 21<sup>st</sup> century.

Although the central focus of this dissertation is the amniocentesis procedure and how it is understood, negotiated, and experienced for Mexican-American women, it is first necessary to provide a background of my participants' understanding of their Mexican-American/Chicana identities as shaped by the cities in which they live; their elders' migration stories; their (in)ability to speak Spanish; their relationships with partners and family members; and their constant, daily negotiations of religion and spirituality. All too often research studies analyze the Mexican-American/Chicana subject without thoughtful, in-depth, and engaged discussions of their subjectivities and lived experiences that provide the backdrop for the phenomena under exploration. A

discussion of these various cultural factors is necessary for various reasons: (a) the changing racial and ethnic demographics in the U.S. call for a more nuanced and careful examination of Mexican-American experiences (Johnson, 1997), (b) the assimilation experiences, struggles, and resistance of Mexican-American women can help illuminate how they negotiate their generational status with their ethnicity and nationality, and (c) race, ethnicity, gender, and language are important factors for Mexican-American women as they experience and make sense of their existence in an anglocentric, sometimes xenophobic society (Castillo, 1994). Thus, this section will discuss the four primary themes that together shape and comprise the participants' identities: ethnic identification, language (in)abilities, the role of religion and spirituality, and relational gender politics.

### **Hispanic, Chicana, and Mexican/American: Ethnic Identification**

The intensity of the terminology debate comes  
as no surprise, then, for it echoes people's struggles  
for non-racist—indeed, anti-racist—ways of defining themselves.  
~Elizabeth Martinez (1998), p. 3

The first theme that is a key component of the participants' identity is the term(s) they use to encapsulate and describe their ethnicity. By ethnic identity, I mean the various ways in which an individual identifies with a particular ethnic group or groups (Doan & Stephan, 2006; Sanders, 2002). As numerous scholars have noted, one's ethnic identity is not only an important source of self-identification (Doan & Stephan, 2006; Phinney, 1991), but a positive identification with an ethnic group provides members of minority groups with the opportunity to reject Anglo stereotypes, e.g. Mexican women

in this country are all immigrants who abuse the welfare system (Doan & Stephan, 2006; Phinney, 1991).

During the interviews, participants were asked what term they would use to describe their ethnicity and how important this identifier was to them. Two of the most glaring differences between the participants in Houston and the participants in San Diego were the salience of their ethnic identity as a component of their overarching sense of self and the terms participants used to classify not just their ethnic background, but also their perception of how they visualized the world, their place within the world, and the role of their cultural values and moral values. As a result, the two main codes for this category were the Hispanic identity and the Chicana/Mexican identity.

#### **“Hispanic—That’s What I Am”: Houston Participants and the Hispanic Identity**

When asked about their identity, the Houston participants overwhelmingly and without hesitation stated that they identify as Hispanic. Out of 15 participants, 14 women immediately responded that they were Hispanic; yet, when probed further, they experienced difficulties trying to express exactly *why* they identified as Hispanic because for them, it just was not a very salient component of their identities. For example, Lourdes, a 32-year-old mother of 4 stated that she is Hispanic but “it’s not really that important to me.” When probed about why, she responded with, “If you know me, I’m not very Mexican at all. I’m from here. I’m more Americanized than that. We didn’t even grow up on Mexican food. We had Hamburger Helper.” In this statement, Lourdes not only expressed her lack of identification with her ethnicity, but she also drew upon her lack of Mexican food growing up to further explicate that she is more American than

Mexican. Similarly, Maura, a 32-year-old mother of one, described herself as “more American” and distanced herself from identifying as Mexican because of where she and her elders were born:

I would say Hispanic. Mexican-Americans came from Mexico and are now here in America. I’m an American because I was born in America. I’m an American.

My mother’s from here, my grandmothers are from here, my great-grandmothers are from here. I’m Hispanic because I’m American, and that’s that.

This notion of being from *here*, not there, of being born in *America*, not Mexico, was a resounding explanation for why the majority of the Houston participants identified as Hispanic, not Mexican or Mexican-American. Just like Lourdes and Maura, Paula, a 33-year-old mother of two, stated that she identifies as Hispanic because “I’m not from Mexico. I mean, I embrace my culture, but I’m not from over there, you know? My parents and grandparents aren’t from there either. They’re from here.” Last, Yesenia, a 33-year-old mother of two, was very adamant that she was *not* any sort of Mexican or Mexican-American. She identifies as Hispanic because “I was born here, my parents were born here, my grandparents were born here... Hispanic. That’s what I am. That’s what we are.”

Thus, for the majority of the Houston participants, being Hispanic meant being an American. It conveyed being born here in America, having a lineage that came from Texas, and in some instances preferring their American side instead of their Mexican side. The participants defined Hispanic not by having a mixed lineage (Mexican and Spanish), but by very adamantly drawing a dichotomy between being of *eso lado* y *otro*

lado<sup>3</sup>. Being Hispanic means not being Mexican, and this is a very important finding in terms of how they communicate their identity. In communicating how they were Hispanic, the Houston participants discursively and performatively denied their Mexican roots and embraced their American identity, as if the two are not and could not be reconciled.

Almost all of the Houston participants repeated in their interview that they were Hispanic and American because they were from here, born and raised in Houston, Texas. The salience of their Hispanic identity was strengthened by their generational status. Most of the participants were second- or third-generation Americans and, as such, took offense when someone called them a Mexican or tried to speak to them in Spanish. As their family had been here for generation after generation, their ties to Mexico grew thinner and in some instances were replaced with their ties to the United States. Instead of being raised with the Spanish language and traditional Mexican meals like tamales, menudo, and tacos, Houston participants recalled their inability to speak Spanish and their lack of Mexican food growing up. This affiliation with the term “Hispanic” and lack of the Spanish language did not characterize the San Diego participants’ experiences; it was quite the opposite. San Diego participants closely identified with a variety of terms that characterized their Mexican ethnicity and were proud of their ethnic heritage, which was exemplified in their abilities to speak Spanish, their love of Spanish music, and their love of Mexico.

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<sup>3</sup> “Of eso lado y otro lado” translates to “Of this side and the other side,” meaning being of both the U.S. and Mexico.

## **“I’ll Always Have My Mexican Roots”: San Diego Participants and the Chicana/Mexican Identity**

As opposed to the Houston participants who mostly identified as Hispanic, participants in San Diego identified with their ethnicity in a myriad of ways, mostly choosing the terms “Mexican” or “Chicana.” Despite the multiplicity of ethnic labels, one thing was clear: the common denominator was their appreciation for and strong affiliation with their Mexican background. Having a Mexican ancestry and background was a source of pride for the participants, and they spoke with joy about Mexican history, Mexican food, Mexican values, and their Spanish language.

For the five participants who identified as Chicana, their adoration of and support for La Raza and El Movimiento stemmed from their families’ involvement in the Chicano movement in the 1960s and 1970s, as well as their academic backgrounds in Chicana@ Studies. The term Chicana was a politicized label that signified their activist backgrounds and their continued *lucha*<sup>4</sup> for Chicano recognition and equality in the San Diego area. Eva, a third-generation Chicana and 31-year-old mother of two, described with pride her great uncle’s role in organizing the Biltmore Hotel educational demonstration in the 1960s and how her activist background was a key contributor to the construction of her Chicana identity:

My great tío was a Chicano revolutionist. He really, really knew what it meant to be Chicano. They took the word back! He was part of the Baltimore 10, he was one of the founders of MECHA, he brought Chicano Studies to SDSU, and he

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<sup>4</sup> “Lucha” translates to “fight.”



was just this huge Chicano figure in our community. I'm so proud of him. He's why I'm a Chicana. I'm carrying on his legacy. Being able to identify with him and what he did, it's like, "No, I'm a *Chicana*."

Eva further described that her uncle and his legacy was one of the main reasons she decided to get a master's degree in community-based participatory research and counseling so that she could give back to the Chicano community and work to create new forms of partnerships and educational strategies for future Chicano generations to come.

Similarly, Esperanza, a second-generation Chicana and 36-year-old mother of two, identified as Chicana because of her family's activist background and her own involvement in the Chicano movement:

I became very conscious at a young age because of my brother, who was involved in the Chicano community. I consider myself a Chicana politically, culturally, and emotionally. It plays such a huge role in who I am and what I do. I went to rallies and organized for 187 when I was 14 or 15. Plus, my husband is Chicano and his father is an old-school Chicano. We call him Chicanosaurus because he was there at the very beginning of the Chicano movement here in California. It plays a huge role in who I am and in who we are as a family.

Being a Chicana was much more than just an ethnic signifier; for these women, being a Chicana signified their families' revolutionary legacies, their pride for La Raza and El Movimiento, and their political and cultural consciousness. This consciousness was also an important component of Judith's Chicana identity. Judith, a second-generation

Chicana and 44-year-old mother of three, had her mestiza consciousness awakened during college when she decided to get a bachelor's degree in Chicano Studies. For Judith, being a Chicana meant having parents and a heritage from both Mexico *and* the United States: "I was therefore Chicana because of my mixed heritage and because I spoke English and Spanish. I was never a pocha.<sup>5</sup> I act and behave like what the scholars out there say is a Chicana. I'm very well conscious of my struggles, my Chicana struggles and the barriers that we're still facing today." This Chicana subjectivity, the consciousness and awareness of racial inequality and educational struggles in the Chicana community and the continued perseverance in improving the Chicano community, was a key component of what it meant to be a Chicana for this segment of the San Diego participants.

Instead of identifying as a Chicana, nine participants identified as Mexican. For this segment of the San Diego participants, they felt that they were Mexican because of their Mexican values, their Mexican upbringing, and their "ability to hold on to [their] roots." Many of them mentioned that they were aware they had an "American side," especially because they were born here, but they were more strongly connected to their "Mexican side" and their Mexican roots. For example, Lara, a second-generation Mexican and 32-year old mother of two, described the many facets of her culture that

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<sup>5</sup> The term "pocha" is typically used to describe a whitewashed female who has left Mexico, who speaks very little Spanish, and who has forsaken her indigenous and Mexican roots. Anzaldúa (2012) describes the relationship of the term "pocho" to the Spanish language when she writes, "The pocho is an Anglicized Mexican or American of Mexican origin who speaks Spanish with an accent characteristic of North Americans and who distorts and reconstructs the language according to the influence of English" (p. 78).

contributed to the construction of her Mexican identity: “I identify as Mexican because my upbringing was very, very cultural. The food that we ate, the music that we listened to, the cultural roles in our family in term of me not being allowed to play sports and having to learn how to cook—it’s all very Mexican.” Lara further described the components of her Mexican identity, such as her favorite music (Los Tigres del Norte and Alejandro Fernandez), her ability to cook traditional Mexican food (tamales, mole, menudo, and frijoles charros), and her longing for México lindo: “I identify myself as Mexican because of the way I was brought up and because I love our culture. It’s so beautiful. It’s such a different way of life. It’s just... beautiful.” Likewise, Luciana, a second-generation Mexicana and 31-year-old mother of one, identifies as Mexican because of her upbringing: “I just say I’m Mexican and that’s it. It’s due to the way I was raised. The people that surround me have more of the Mexican background, the principles my dad raised us with, all of that plays in it. I’m more Mexican than American, even though I was born here.”

Luciana’s sentiment about embodying and preferring her Mexican side over her American side was a common thread linking their Mexican identity preference to the participants’ cultural upbringing. However, the participants’ mothers’ and fathers’ parenting methods and their cultural upbringings were not the sole factor that contributed to their identity as a Mexicana and their longing for Mexico; another important and related factor was their very conscious awareness that they had two sides, their Mexican side and their American side, and that they preferred the Mexican way of life and the Mexican terminology. For example, Maria, a second-generation Mexican

and 40-year-old mother of two, identifies as a Mexicana, even though “I know I’m Mexican-American”:

I still consider myself Mexican. When I was a child, I lived in Mexico for 4 years and really got the feeling of being Mexican. Even though my mom kind of Americanized herself and us, I went to Mexico and realized, “Okay, this is where I come from! This is how it is. This is my foundation.” It’s such a beautiful place. I’m not a Chicana because that’s someone who was born and raised here and is trying to get a hold of their roots. I have my roots, I’ve lived it, I’ve experienced it. That’s why I consider myself Mexican.

For Maria, a key catalyst in her decision to choose being Mexican over being Chicana or Mexican-American was her trip to Mexico as a child. This journey solidified her Mexican identity, as it did for Elena, Flor, and Marisa. Elena, a second-/third-generation Mexicana and 39-year-old mother of one, attributed her Mexican identity to her inability to “fit in with the Mexican-American crowd,” as well as her childhood trips to Mexico:

When I was younger, I went to stay in Mexico with my dad’s family. I got to do all kinds of stuff before I really went to school here, and I learned Spanish and all different sorts of things about our Mexican culture. . . I love it there. Even though I was born here in California, eventually I just decided that I am who I am. I’m Mexican whether anyone likes it or not.

Likewise, second-generation sisters Flor and Marisa, a 31-year-old mother of three and a 34-year-old mother of two respectively, attribute their Mexican identity to their trips back and forth across the San Diego/Tijuana border. Flor recalled conversations she has

with her daughters and their process of realizing ethnic consciousness. Flor's daughters told her one day, "Mommy, my friends were born in Mexico and are Mexican, but we're born here and we're American." During the interview, Flor mentioned that this sort of thinking bothered her because it is the exact opposite of how she and her older family members identify:

I just say I'm Mexican. My daughters are a lot more American than Mexican in the sense of the way they think. I guess I'm not doing a good job with the culture or language part of it. I've always been Mexican and that's that. We grew up in diverse neighborhoods with a lot of Mexicans, and I didn't even have a concept of what it meant to be a U.S. citizen or Mexican citizen. We're so close to the border that even though we didn't live in Mexico, we were back and forth all the time. Back and forth al otro lado.

Flor's older sister Marisa expanded upon Flor's sentiments, noting that "when we were teenagers, we went back and forth across the border so much. That whole experience and where we grew up really made us feel Mexican."

Thus, the two main ethnic identifiers for the San Diego participants were Chicana and Mexican. Surprisingly, only one participant identified as Mexican-American, and no participants identified as Hispanic. For the women who identified as Chicana, this was a highly politicized term that signified both their affiliation with and support of the ongoing Chicano movement, as well as their very explicit and lived consciousness of the

continued struggles that Chican@s<sup>6</sup> face today. The participants who identified as Mexican were also aware of the Chicano movement, yet identified as Mexican because of certain factors like the Mexican values their parents instilled in them, as well as their ability to traverse the San Diego/Tijuana border, embrace and appreciate their Mexican cultures, and speak the Spanish language. This key component of one's ethnicity, the (in)ability to speak the Spanish language, is the subject of the next theme.

### **Spanish-speaking (In)abilities**

So, if you want to really hurt me, talk badly about my language.  
*Ethnic identity is twin skin to linguistic identity*—I am my language.  
Until I can take pride in my language, I cannot take pride in myself.  
~Gloria Anzaldúa (2012), p. 81

The relationship of one's language and language abilities to their ethnic and cultural identity is certainly not new territory in Chicana feminist scholarship. Foundational scholars such as Gloria Anzaldúa (1983; 2012), Cherrie Moraga (2011), and Ana Castillo (1994), along with more contemporary scholars such as Michele Holling and Bernadette Calafell (2011), have written about the important role of being able to speak one's native language and how it factors into the construction and performance of one's ethnic identity. The ability to speak Spanish is important because it can connect a person to various components of their ethnicity, including understanding lyrics to Mexican/Tejano/Norteno songs, understanding menus and ingredients in Mexican restaurants, and being able to help a person who speaks only Spanish with a request. Moreover, the ability to speak Spanish can also connect people to both their

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<sup>6</sup> I use the term "Chican@s" to include both the masculine (Chicano) and feminine (Chicana) variations of the term.

mythological homeland (Aztlán) (Anzaldúa, 2012; Castillo, 1994) and what they consider to be their literal homeland, whether it be Mexico or the homeland they construct as they traverse the U.S./Mexican border (Flores, 1996). Although the interview protocol did not include a question about their ability to speak Spanish, participants from both cities repeatedly spoke about the role the Spanish language played in their perceptions of their ethnic identities. For the Houston participants, there was a severe Spanish language barrier, whereas the San Diego participants mostly grew up learning Spanish and English simultaneously. This (in)ability was a key factor in the doubting of and reaffirmation of the participants' Hispanic, Chicana, and Mexican identities.

#### **“I Don’t Know Spanish. It Doesn’t Really Matter”: Houston Participants and the Inability to Speak Spanish**

For the Houston participants, their relationship to their Spanish-speaking (in)abilities was quite a contested terrain during the interviews. Although the interview protocol did not include a question about their Spanish-speaking competencies (only about the term they would use to categorize their ethnic identity), the topic surfaced within almost every interview as participants spoke about their inability to speak Spanish well and how this inability often called their ethnic authenticity into question. Participants often expressed surprise and offense at the audacity of others to presume they spoke Spanish.

For example, when speaking about how she does not know Spanish and how it is not a big problem for her, Lourdes recalled a time when she was at the grocery store and

a Spanish-speaking person asked her a question: “I always get the people who come up to me and try to speak Spanish. And every time, I’m like, ‘I don’t know what you’re saying. I can’t help. I’m sorry.’ I mean, my parents never taught me Spanish, and it doesn’t really matter to me. We live in America. People need to learn to speak English!” Ysabel, a Hispanic female and 33-year-old mother of two, echoed Lourdes’ statements: “I guess I would call myself Hispanic, but I don’t know Spanish. I don’t know anything of my culture. My parents didn’t really talk to us more about it. Everybody always assumes I know Spanish, and I’m like, ‘Sorry, I don’t!’ It doesn’t really matter to me.” Likewise, Maura recalled a particularly embarrassing moment from her past when she worked at a department store. A woman asked her a question in Spanish about coupons, and Maura could not respond to her in Spanish because she does not know how to speak it, even though she can understand Spanish when it is spoken around and to her:

I said, “Um, no entiendo.” I knew how to say some things to let her know I didn’t understand what she was saying, but I wasn’t comfortable with answering her questions. In Spanish, she tells another lady, ‘What kind of parents does she have that they didn’t teach her Spanish?’ *I was humiliated. I was mortified.* She saw my color, she saw my skin, she assumed that I could speak Spanish. My dad got so upset and told me, “The next time somebody tells you that, you tell them ‘If you’re going to be in this country, you need to learn how to speak *my* language.’” You know, he’s so right. We’re in America. They need to learn how to speak English, not the other way around.



Thus, for the majority of the Houston participants, most could not speak Spanish well, even though they understand various Spanish terms and phrases, and this language inability was not an important component of their identity.

Instead, this lack of identification with the Spanish language often propelled the participants to respond with a bit of disdain when Mexican people tried to speak to them in Spanish. Not only is their inability to speak Spanish perceived as unproblematic, but there is evidence of intraethnic offense as the participants constantly mentioned that people who live here in the United States should speak English, regardless of how long they have lived here or where they are from. Moreover, this inability to speak Spanish was an indicator of the participants' inability to authentically perform their ethnicity, which often called into question their ethnic authenticity, despite their dark skin and ethnically marked bodies. The San Diego participants did not share these sentiments and experiences, though. Whereas the Houston participants did not speak Spanish and preferred that everyone speak English, most of the San Diego participants learned Spanish and English simultaneously and were very proud of their Spanish-speaking abilities.

### **“Of Course I Speak Spanish. I Was Raised on It!”: San Diego Participants and the Ability to Speak Spanish**

The majority of the San Diego participants spoke both Spanish and English fluently and were proud of their Spanish-speaking abilities. They noted that they learned both English and Spanish simultaneously while they were growing up because it was an important value to their parents. Most of the participants had one parent who was a first-

generation American and one parent who was a second- or third-generation parent, so learning Spanish at home and being able to speak with their parents fluently in Spanish was a very important part of their home life. Not only was it important for them to converse in Spanish with their elder family members, but it was also a means of transmitting various facets of the Mexican culture, like canciones, dichos, and cuentos de la historia de la familia. Speaking Spanish was like a second skin for the San Diego participants, and most of them noted that they could not imagine a life where they did not speak Spanish.

For Eva, speaking Spanish gave her the opportunity to connect with her older family members and to reaffirm her Mexican/Chicana identity:

People always question my authenticity because of my blonde hair and blue eyes until they show up to a family event and realize that we all speak Spanish. The cousins, we hang out and all speak Spanish, and I always have to speak to my elders in Spanish. They won't have it any other way. We even sing Happy Birthday in Spanish! So then, you know, people are like, "Oh, you ARE Mexican!" Why would I even lie about that? It's the stupidest thing.

Similarly, Judith, Lara, Anita, Marita, Esperanza, María, Flor, Marisa, and Elena all learned Spanish at a young age so that they could communicate with their older family members and even now transmit this family value to their own children by speaking to them in both English and Spanish. Lara recalled why her parents made her learn Spanish at a young age:

I speak to my children in Spanish and English because that's how I was taught growing up. It was English all day at school, and as my parents did with my brother, we weren't allowed to speak English at home after 6 o'clock. We could speak English all we wanted until 6pm. At 6pm, my parents turned off their English brains and we were all about Spanish until the morning. That's how I kept both my languages. I'm so thankful for that.

Likewise, María had the same house rules she was young, noting "The only rule was that we had to speak Spanish while we were at home. That was our house rule. It really helped me stay fluent in both languages!" Judith also had to learn both English and Spanish growing up so she could communicate with older family members: "Yeah, I learned both Spanish and English growing up. My parents wanted me to speak to them in Spanish, even though they knew English. It was important to them." Thus, for the majority of the San Diego participants, learning Spanish and English simultaneously was a source of pride, and their Spanish-speaking abilities were definitely a component of their ethnic identity that they were proud of.

Taken together, the Spanish language occupied a drastically different role in the participants' lives and ethnic subjectivities. For the Houston participants, their inability to speak Spanish was a topic that elicited uncomfortable and embarrassing recollections and often resulted in small fits of audacity that Mexican people would speak to them in Spanish and expect them to speak Spanish in return. It often called their ethnic authenticity into question and was most certainly a site of discomfort. For the San Diego participants, however, their ability to speak Spanish was a proud family value that was

instilled in them at a young age and is one that they are transmitting to their children by simultaneously teaching them Spanish and English as well. The ability to speak both Spanish and English barred the participants' complete assimilation into the Anglo mainstream culture (Johnson, 1997).

Although it might seem that up to this point I am constructing an unnecessary dichotomy between the Houston participants and San Diego participants, that is not my intention. The two groups might have different experiences pertaining to their ethnic identification and language abilities and the role that these two components play in the construction and performance of their identities; however, they did share similar perceptions of another important component of their ethnicity: their religion and spirituality.

### **Religion & Spirituality**

The relationship between the Mexican culture and Catholicism is well documented and undeniable. Dating back to the Spanish Conquest and the early 1500s when La Virgen de Guadalupe first appeared to Juan Diego near Mexico City, Catholicism has since been one of the strongest and most important ideologies and structures of the Mexican culture (Castillo, 1994). Mexican mothers and grandmothers of generations past have venerated La Virgen for her example of how to be a good Mexican woman and also for her strength, comfort, and protection. Given the importance of the Catholic religion in the Mexican culture and the proliferation of academic discourses that discuss and theorize its role in Mexican women's healthcare (Atkin, Ahmed, Hewison, & Green, 2008; Seth, Goka, Harbison, Hollier, Peterson,

Ramondetta, & Noblin, 2011; Vidal-Ortiz, 2010), I wanted to take a step back and explore how religion is socially constructed for the participants and the role that their generation plays in their understanding of and performance of their religion in their day-to-day lives. Yes, the Catholic religion is still absolutely an important pillar of the Mexican culture in Mexico, but how is it understood and practiced by second- and third-generation Mexican-American women? Is it still an important cultural structure? What is the role of religion in their everyday lives?

Although the Houston and San Diego participants' social constructions of their ethnic identity and their language has diverged, the main similarity that the two groups share is their understanding of their religion. The two groups (25 out of 30) overwhelmingly identified as some sort of Catholic at some point in their lives, yet the salience of their Catholic identity varied. On the religious performance spectrum, some participants identified as non-practicing Catholics, non-Catholic Christians, or spiritual believers who were raised Catholic but no longer practice any sort of organized religion.

#### **“I’m a Diet Coke Catholic!”: The Non-practicing Catholic**

For those participants who still identified as Catholic, they overwhelmingly prefaced their statement during the interview as, “I’m Catholic, but...” The role of the Catholic faith was so important to their families that they were baptized Catholic when they were infants, did their first communion, and went to church on a regular basis when they were younger, but as they have grown older, they participate in the Catholic religion less and less. The participants also described their parents' devout dedication to the Catholic faith and their impeccable mass attendance; for the participants, their

distance from the faith and their status as a non-practicing Catholic somewhat bothered their families, yet it certainly did not keep them from sleeping at night.

For example, Mireia, a 44-year-old mother of two from Houston, noted that she is Catholic, but “not really”: “Well, I’m Catholic, and if someone asks, I’m Catholic. But I never really... We don’t go to church very often.” Similarly, Paula, a 33-year-old mother of two from Houston, laughed as she mentioned, “I was brought up Catholic, but I don’t know about practicing it!” Yesenia, a 33-year-old mother of two from Houston, shared the same sentiments and also laughed as she described how she practices the Catholic religion:

We’re Catholic, but we’re not married in the Catholic Church, yet sometimes we follow Catholic ways. We pick and choose. Like, if the Catholic Church was on the shelf at the grocery store, here’s how I would be: I like you, and I like you! You, that tradition, you’re looking good over there! But not you, you’re too old school for me right now.

This notion of being a “diet coke Catholic,” of picking and choosing certain components of the Catholic faith, was a practice shared by many of the San Diego participants as well. Marita, a 34-year old mother of two who identifies as Mexican, mentioned that she followed the Catholic faith when she was younger because she was forced to, but she is much more relaxed about it now that she is older: “I know I’m Catholic because my family is Catholic, but I don’t follow it very much. I only follow it to a certain point, like to baptize the babies or go to a quinceañera, but that’s it.” Maria, a 40-year-old mother of two, also noted that she has “a Catholic background, but I don’t practice it as much as

my mother wishes I did!” Finally, Juana, a 32-year-old mother of one, also described her relationship with the Catholic Church as one that’s “not the greatest”: “I’m Catholic, yeah, but I’m not the greatest Catholic. I don’t go to church very often. It’s just every once in a while.”

Thus, for this segment of the Houston and San Diego participants, they were born and raised Catholics, yet as practiced the religion less as they got older. The participants noted that they still appreciated the Catholic faith and the roles it played with their parents and older family members, yet they were not very interested in being fully practicing Catholics. Instead, they preferred picking and choosing which traditions and sacraments were most valuable in their lives, such as baptizing their children “for the sake of their souls” or going to mass every once in a while on holidays or for family events. Not all participants shared this same sentiment regarding the Catholic religion, though; some participants were born and raised Catholics, but chose another denomination altogether as soon as they were “old enough to choose.”

#### **“I Was Catholic, but I’m a Baptist Now”: The Non-Catholic**

Despite the fact that the overwhelming majority of the 30 participants were born and raised Catholic, about 1/3 of them chose another Christian denomination when they were older because “the Catholic faith just wasn’t doing anything” for them or because they wanted to try something different for a change. Lourdes described growing up in a traditionally Catholic family, yet converted to being a Pentecostal when she was older: “Yeah, I’m Pentecostal now. I just didn’t like the way Catholic mass was run. Pentecostal services are much more involved.” Similarly, Dulce, a 34-year-old mother of

two from Houston, stated, “I *was* Catholic. I grew up Catholic. But as I got older, I started going to Christian churches. I don’t mean to be rude, but you start falling asleep in Catholic church! You know, I’d rather be clapping my hands and dancing!” Ysabel also expressed her preference for non-denomination Christian churches: “I was Catholic at one point, but now I’m not. I go to a non-denomination church, and I like it much more there. It’s about God, not the religion.”

Participants from San Diego also mentioned preferring non-denominational churches to Catholic churches. Judith described her family as a good, Catholic, God-fearing family, yet she transitioned to non-denominational Christianity once she grew up: “Yeah, I grew up with my Catholic family background. I didn’t really understand the whole concept of what it entailed being Catholic. I practice Christianity now and go to a Christian church.” Judith further noted that she preferred non-denominational Christian churches to churches with an organized religion (Catholic, Lutheran, Methodist, etc.) because “they’re more about God and less about rules.” Similarly, Juanita, a 32-year-old mother of one, described her family as “hardcore Catholic,” yet recently transitioned to a Christian church with her dad: “Yeah, they’re hardcore Catholic. I was raised Catholic, but recently started going to a Christian church with my dad. It’s more spiritual than the Catholic church.”

Thus, for this segment of the participants, despite the fact that they grew up Catholic, their religious preferences changed as they aged. Most participants chose non-denominational churches because they felt that these were more “spiritual” locations, largely due to the interactive nature of the church service. The preference for “singing



and dancing” churches caused these participants to forego the traditional “sit, stand, kneel” model of the Catholic Church in search of something more cooperative. For the last segment of the participants, however, more interactive church services were not enough to keep them affiliated with any sort of religion. Instead, these participants preferred spirituality and faith instead of organized religion.

### **“I Don’t Practice a Religion, but I’m Definitely Spiritual”: Non-organized Spirituality**

The final segment of participants described how they were born and raised Catholics, yet completely distanced themselves from any sort of organized religion as they grew older. The two primary reasons that they decided not to identify with any organized religion was because they were unsure which one was best for them and because they were unhappy with what they perceived were “oppressive religious ideologies.”

For the few participants who were unsure of which denomination would best serve their needs, they decided to not identify with any organized religion and simply “live believing.” For example, Isa, a 34-year-old mother of four from Houston, spoke in depth about the various struggles she experienced over the course of her life and how this contributed to her somewhat wavering religious affiliations and beliefs:

You know, with all the crap I had to deal with from my father, my ex, my husband... I’ve definitely had some hard times in my life. Yeah, I was reared Catholic, but then when I got pregnant with my first and I was unmarried, let’s be real: the Catholic Church wasn’t really too supportive of that. There are just

certain things with the Catholic Church that I don't agree with. It's the same with Baptists, Lutherans... I believe in God 100%, but not so much with the religion itself.

Isa further discussed that she never really felt at home in the Catholic Church because she had her first two daughters when she was unmarried and that she always felt ostracized, like she did not belong. This notion of organized religion being too stringent and oppressive was also expressed by some of the San Diego participants. Beatriz, a 33-year-old mother of two, grew up as Catholic but distanced herself from the organized religion, even though she still believes in God: "You know, I've just been questioning the whole idea of religion lately. I really disagree with the Catholic religion and what it preaches and believes, but I still believe in God. That spiritual relationship keeps me going."

Eva, a third-generation Chicana and 31-year-old mother of two, spoke with pride about the role of Catholicism in her family. Since her Nana, her grandmother and the family matriarch, was a devout Catholic, the Catholic religion was a source of pride and comfort for her family. As Eva went to college and started forming her Chicana consciousness, she eventually distanced herself further from Catholicism more specifically and from organized religion more generally:

I don't practice a religion. I'm sure you can understand, though, that it's so hard to separate the Catholic religion and the Mexican culture. They're so intertwined. Even though it still has a very present role in my family's lives, I don't practice it anymore. I'm still proud of my family for practicing it, but I started pulling away

from religion in general and actually hated it for a little while. I don't hate it anymore, though. I still believe in God, but for me, I'm more spiritual. I believe in being a good person. I just feel like organized religion is a systematic way for people to segregate one another.

For Eva, it was not about religion as much as it was about spirituality and good karma. Marita, a 34-year-old mother of three, agreed with Eva's assessment of the oppressive nature of organized religion. She admitted to being raised in a Catholic family, yet does not practice religion because, frankly, she does not like "some man" telling her what to do:

With the Catholic religion, God always decides when you want to have kids or not, when you get married, he decides everything! I only followed the Catholic religion when I was little because I was forced to. When I turned 18, though, I was like, "No, no more." Why do I always have to obey someone who has different opinions than I do? Like, you can read a book and interpret it in different ways. If I interpret it in a different way and put it in another book, it's going to be my opinion. Once I got to college, I was like, "Nope, I'm done." I don't practice any religion now.

Finally, Elena, a 39-year-old mother of one, mentioned that the "good ol' Catholic guilt" was what kept her going to the church. Similar to Eva and Marita, though, she quickly decided to not practice a religion once she got to college: "When I was growing up, it was more of a 'You need to go to church and do these things!' It was that good ol' Catholic guilt. The day it became my choice not to, I stopped. I just got sick of it."

Esperanza, a 36-year-old mother of two, also rejected Catholicism when she was older and turned toward a “more spiritual path”: “I go to Native American ceremonies like sweat lodges. I also do Danza Azteca and other sorts of indigenous/Native American rituals. This is my spirituality, my spiritual path.”

Thus, for this segment of the participants, a very conscious decision was made to reject the Catholic religion and *all* organized religions because of the oppressive beliefs and mandates supported and practiced by each religion. All of these participants had at least one child out of wedlock and felt that the Catholic religion did not truly support them or accept them. Moreover, when the participants went to college, they became more conscious of how Catholic beliefs and traditions were too demanding and clashed with their lifestyles and preferences. However, despite the rejection of organized religion, one factor remained true: it was important for the participants to maintain some sort of connection to a higher power, whether it was a Christian God or other spirits.

For both the Houston and San Diego participants, religion was an area that the participants negotiated and amended according to their life needs. The Catholic religion was not as important in the participants’ lives as has been suggested by both personal experience and previous academic scholarship, and this is attributed to numerous factors, including preferences for the way mass is operated, a critical consciousness that led to a constant questioning of the patriarchal dominance of Catholic ideologies, and the need to still have some sort of spiritual affiliation without being attached to an organized religion. Although organized religion was not a very salient component of the participants’ lives, almost all of them expressed the need to remain connected to a higher

spiritual power. The participants' perceived relationships to their religious/spiritual higher powers were enhanced by one additional component of their lives: their relationship with their partner/spouse.

### **Relational Gender Politics**

The fourth and final identity theme that arose out of the interviews centered upon participants' relationships with their husbands. All of the participants identified as heterosexual. Moreover, 15 had remarried, 13 were still married to their first husband, and 2 were single. This theme is an incredibly important component of the participants' ethnicities and ethnic identities, as it was inextricably linked to every other component of their lives, such as their relationship to religion and spirituality, their satisfaction with their healthcare experiences, and even the salience of their ethnicity to their identity.

Academic scholarship has abundantly theorized and explored Mexican intimate relationships. Relationships between Mexican men and Mexican women have traditionally been defined according to the machismo/marianismo dichotomy. This dichotomy explicates the various ways in which patriarchy manifests itself in the Mexican culture. It positions men as the macho head of the household who "calls the shots," so to say, and women as the passive familial martyr. The machismo/marianismo dichotomy even applies to sexual aspects of intimate relationships, as machismo is typically associated with negative health behaviors such as promiscuity, unprotected sex, spousal abuse, aversion to contraceptives, and family conflict (Galanti, 2003; Gallo, 2009; Tamez, 1981). This construction of machismo, however, is what Chicana feminist scholars often refer to as "false machismo." First coined by Gloria Anzaldúa (2012),

“false machismo” refers to the negative construction of the Mexican man as an abusive, hypersexual drunkard. Rather, machismo can also signify a man taking care of one’s family, providing for the family’s well being, and being a supportive and encouraging father and husband (Castillo, 1994).

On the other end of the spectrum, Mexican women who perform the *marianismo* role often place their family needs first and sometimes privilege the wants and needs of the husband and children above their own. Chicana scholars have long written about and analyzed machismo and marianismo in Mexican intimate relationships and how this gender role dichotomy is linked to centuries-old constructions of la mujer Mexicana in relation to el hombre Mexicano. Ana Castillo (1994) provided the historical backdrop for contemporary Mexican gender roles and noted that machismo and marianismo are grounded in religious and historical constructions of the Mexican woman as men’s property both through childbirth and marriage. The notion of being a commodity that men can own manifested itself within interpersonal relationships, as men assumed the head of the house and women followed suit in the passive role. Cherrie Moraga (2000), for example, wrote in detail about her mother’s relationship with her father and sons and how this affected their family dynamics and “women’s place” within the family. Moraga (2000) recalled how 40 years prior, her mother had to wait on the men in the family and how she, as a teenager, also had to wait on all the men in the family, despite her discontent with doing so. Gloria Anzaldúa (2012) also wrote about how being a female unequally positioned herself within her family, as female family members were often expected to serve the men in the family and excel at their domestic duties.

Thus, given historical and more contemporary discourses about traditional Mexican gender roles, I sought to explore how relevant the machismo/marianismo dichotomy is to second- and third-generation Mexican relationships. Do the traditional gender roles still occur in more acculturated relationships? If so, to what extent, and in what ways do the women negotiate power within their relationships? Utilizing an interpersonal communication lens, I am interested in the relational gender politics occurring within the participants' relationships. By relational gender politics, I mean the various ways in which women negotiate power with their spouses and partners and how they view traditional Mexican gender roles in relation to their marriages and relationships. Chicana feminist scholars such as Aída Hurtado (1998) and Patricia Zavella (1987) have noted that gender relations have been explored by white feminists, yet now scholars need to explore and understand intragroup relations between minority women and their spouses from a feminist perspective.

Although I did not explicitly ask participants about their relationships with their spouses, conversations about discussing the amniocentesis procedure with their significant others ignited further conversations about their relationships with their past and current spouses, including infidelity, religious (in)compatibilities, and “who calls the shots.” The two main codes that emerged from this section of the interviews include first-marriage woes and second-marriage bliss, as well as equal and supportive first marriages. Although some participants had first marriages that were characterized by arguing, conflict, and infidelity, a majority of the participants had egalitarian second marriages.

## **“My First Marriage Just Didn’t Work”: First Marriage Woes & Second Marriage Bliss**

This code focuses on how approximately ten participants had been separated or divorced and happily remarried. When discussing how their first major relationships/marriages had ended in separation or divorce, both groups of participants overwhelmingly noted that they had been cheated on. This infidelity eventually led to divorce, regardless of how many children they had and regardless the difficulties associated with being a single mother. The infidelity occurred at various relational stages, including before, during, and after pregnancies.

When speaking about her first husband, Lourdes, a 32-year-old mother of four from Houston, noted how the person she divorced was not the same person she married. She noted, “My first husband turned out to be a total scumbag. Lying, cheating, the works!” In recalling her first relationship with her common-law partner (her first serious relationship), Isa, a 32-year-old mother of four from Houston, also spoke about his “scumbag” nature: “Oh man, he was the father of my first daughter. He was my high school sweetheart! In the end, I found out how unfaithful he was. He would cheat on me with his female friends and stuff like that. It was so unexpected. Jerk.” Houston participants Nayara and Isabel, a 33-year-old mother of four and 33-year old-mother of two respectively, also mentioned their husbands’ infidelity as being the main cause of separation and divorce; what makes their situations unique, however, is that their husbands’ relational infidelity occurring *during* their pregnancies. “My first husband cheated on me when I was pregnant with our third child,” Nayara said. “He ended up



getting another woman pregnant. After our third child was born, I immediately divorced him.” Isabel also left her husband after her first son was born:

My ex made me go crazy because he just kept playing with my mind. When I was pregnant with our son, I found out when I was 3 months pregnant that his mistress had a son 3 months before that! I even caught him with her at her house... I was just so blind. He was so abusive. I had to raise my son by myself because I didn't want to be a part of what he was doing.

Similarly, Juana, a 32-year-old mother of one from San Diego, found out she was pregnant with her first child, she got “blindsided” by how her ex-common law spouse reacted:

When I got pregnant, instead of him stepping up to the plate, he decided he didn't want to be a part of it. He told me that if I wanted to continue a relationship with him, I had to terminate the pregnancy. If I wanted to keep the baby, I was on my own. He even threw me out of our home! I then went and asked for my mom's help and she said no, so I ended up temporarily at a homeless shelter because I just couldn't afford everything and I had nowhere to go. We got back together shortly after, and then I found out he had been cheating on me the entire time. I left him for good.

For these participants, it became clear that their spouses' infidelity was very unexpected and despite the duration of their relationships or their strong bonds, the damage was irreparable.

For the other five participants, they were divorced and remarried because what they perceived were irreparable communication issues during their first marriages. The two main communication issues mentioned were lack of openness and lack of support. For example, Noelia, a 37-year-old mother of two from Houston, described her first husband and her second husband as total opposites. She mentioned that the primary reason she and her first husband got married was because she got pregnant, and during the marriage she really got to know what he was like. One of the major problems, however, was that he never fully opened up to her, even after five years of marriage:

It's like he was there, but he wasn't really there. He was so distant throughout the whole thing. He would never *really* tell me what he was thinking or feeling, and we just kept distancing from each other. We eventually started sleeping in separate rooms and then just divorced each other. He just wouldn't talk to me or open up to me.

Similarly, Maura, a 32-year-old mother of one from Houston, described how her first marriage of 7 years eventually dissolved:

We kept trying to conceive and just didn't have any luck. I even went to a fertility specialist and did treatments for about 3 years, and still nothing worked. Our infertility problem eventually ended up being one of the reasons we separated. We just kept growing further and further apart from each other because I had a hard time getting him to talk to me. I know it hurt him, but you know what? It hurt me, too, for him to totally shut down on me.

For these two participants, reproductive concerns and issues ended up minimizing their husbands' open lines of communication, which they perceived eventually ended their marriages.

In addition to the lack of openness between spouses, the lack of marital support also caused a huge strain on some of the participants' first marriages. The women consistently noted that all they really wanted was for their partner to support them. In addition to Noelia and Maura noting that their first husbands did not support them during their marriages or pregnancies, other participants recalled times when their husbands also did not support them in any of their endeavors. For example, Eva, a 31-year-old mother of two, spoke fondly of her first spouse, yet noted that she just could not get over his lack of support: "I loved him so much. I mean, I had a son with him! But he wasn't the most supportive guy, and he didn't have the most loving nature. It just didn't work out."

Esperanza, a 36-year-old mother of two from San Diego, also mentioned that her first husband was not supportive. While their clashing religious beliefs certainly did not help the situation, Esperanza kept referring to his lack of support as the most central problem of their marriage: "Well, it didn't help that he was a very religious Christian and that he didn't agree with my Native American spiritual path. The biggest thing was that he didn't support me. It was just so stressful!" Last, Juana, a 31-year-old mother of one from San Diego, mentioned that her ex-common law spouse's lack of support covered a range of events in their lives, including the birth of their first child and also her dreams of finishing her bachelor's degree once her son got older: "It was very

difficult. At that point, I was in the Army reserves and was going to school full-time. He was totally against having a child, and that took a toll on our relationship. He didn't support me or what I needed at all... at all. I felt like I was alone the entire time."

Although marital infidelity, one of the most widely supported and agreed upon machismo behaviors, was evident in some of the spousal relationships, as well as lack of communication and marital support, every single participant ended up in what they described as supportive, loving marriages after their divorces. Lourdes mentioned that her current husband supports her throughout everything: "He's so amazing. He was willing to take on extra night shifts at work just so that I could quit working full-time and go back to school and finish my bachelor's degree. That means a lot to me!" Nayara also discussed how much her current husband supports her: "After my first husband, I was really hesitant to get involved again. My husband is there for me, he supports me, and he doesn't mind that I stay at home with the kids. It's really important to me that I can do that." In addition to the support that participants receive from their spouses regarding childcare, Esperanza noted that her husband's support is very holistic: "Not only does he support me working full-time, but he also supports my Native American spiritual beliefs by partaking in the religion with me. It helps strengthen our marriage, too. We have a mutual admiration of and support for each other."

Thus, although half of the participants went through a marriage where their husband performed behaviors that are traditionally defined as macho, including marital infidelity and communicative distance, the positive side of this code is that the participants remarried men who they described were more supportive, more loving, and

altogether just a better fit for them. These same characteristics were also used by the other 13 participants who were still married to their first husband to describe their husbands' support and communication patterns.

### **“He’s My Biggest Support”: First Marriage Support & Partnership**

For 13 participants, they were still happily married to their first husband. Marriages ranged from five to 20 years, and participants consistently noted that having their husbands' unwavering support was one of the key factors to a successful marriage. Estrella, a 44-year-old mother of two from Houston, spoke lovingly of her husband and even described all the quirky nicknames they have for each other: “He’s my honey bear! We’ve been married for longer than I can remember, and what helps is that we’re on equal ground. He supports my career, he helps me at home and with the kids, and he believes in me. That’s what really makes it work.” Mireia, another 44-year-old mother of two from Houston, talked in depth about how her two pregnancies left her with unusually long recovery periods. Her husband not only took great care of her and their two kids during her postpartum recovery, but after 8 years, he is still “knocking it out of the park”: “He’s my best friend. He owns his own business, yet that doesn't stop him from being there for me or the kids. He’s like my partner!” Yesenia, a 33-year-old mother of two from Houston, also utilized the term “partner” to describe her husband: “We’ve been married for 5 years, and we just work so well together. We’re like a team, a unit. He’s my partner. We both work-full time, but we share all the child duties and house duties equally.” Finally, Anita, a 32-year-old mother of one from San Diego, also

described her husband as her “life partner”: “He’s just so involved with our son, and he’s my partner in crime. He was my high school sweetheart, and we’re still going strong!”

This notion of marital support being equivalent to a marital partnership where gender roles are more egalitarian, meaning men and women treat each other as relational equals and take equal responsibility for taking care of the home and the children, was also evident for the San Diego participants. They described their relationships, however, with more explicitly feminist terms, and this is likely due to the fact that many of them had some college background or even bachelor’s degrees in Chicana@ studies. This segment of the participants spoke about their undergraduate courses in Mexican gender roles, Mexican cultural norms, and Mexican/Mexican-American history. This background ignited a consciousness for them that helped give them a more assertive voice in their intimate relationships. Judith, for example, described that she would not “take any crap” from her husband:

With the men in my family, raising a child didn’t involve changing diapers, taking care of them when they’re sick, going to teacher conferences, helping them with their homework, or anything like that. The father is a provider, like you would expect in traditional Mexican families. That’s his one and only role. I promised myself I wasn’t going to put up with that during my marriage... not at all. I told him in the very beginning very clearly that I wasn’t going to stand for that, and to this day, I haven’t. He’s wonderful. We have a special needs child, and he’s so great with her and the two kids. I’m very thankful for him.

Judith further discussed with me that she would have had a much more difficult experience attaining her master's degree if it was not for his support. Her husband also helps with childcare and supports her educational and career goals, which is something she described as "invaluable." Marita, a 34-year-old mother of two, was also very outspoken about her awareness of lopsided relational gender norms for older Mexican generations and expressed that those outdated gender norms would not occur in her marriage:

I don't follow the ways behind me. It's my own way of being. My environment has always been like, "This is what is going to be dictated, this is what you're going to do," and I really disagree with that. I still know people my age, as well as older family members who say, "Oh, you have to obey your husband. You can't look at him when he's talking to you." But I'm like, "No!" I respect other people's opinions and ways of living, but that's not for me. I tell my husband anything and everything! I speak out! We're on equal ground in this marriage.

Last, Luciana, a 31-year-old mother of one, discussed with me how she and her husband had a very explicit conversation when they first started dating about how she "wasn't going to put up with it": "Given the way some of our older family members act, I told him I wasn't going to put up with any of that bossing around, making me a servant crap. He agreed that it was terrible. He's not really like that, though, but I figured I would make it clear, just in case!"

Thus, for this segment of the participants who were still married to their first husband, they consistently noted that the most important ingredient for their marriages'

success was support and partnership. Although I did not prompt the participants with questions that explicitly asked about supportive relationships and gender roles, they repeatedly mentioned that support for them meant having a husband who respects them, helps out with household and childcare duties, supports their career and educational goals, and treats them as an equal partner.

### **Discussion: Who is the (Contemporary) Mexican Woman?**

This chapter has sought to explore a topic and join a conversation that is central to both historical and contemporary Chicana feminist scholarship: who is the Mexican woman? Although this chapter on identity might not directly deal with their prenatal screening and testing experiences, it is still an important topic to discuss because their healthcare experiences are directly situated within a complex web of cultural, ethnic, familial, and gendered factors. Although most academic scholarship has focused on what some might consider outdated relational gender norms that traditionally used to govern intimate Mexican relationships, as well as Mexican women's strong identification with the Catholic religion and veneration of La Virgen de Guadalupe. What has not been quite parsed out yet, though, is the role of acculturation as it plays out in Mexican women's lives, such as how it shapes their ethnic identification, their Spanish/English language proficiencies, and their religion. By interviewing 30 Mexican-American women from San Diego and Houston, I gathered a snapshot of how Mexican-American women understand their ethnicity, their language (in)abilities, their religion, and their relationships with their spouses.



First, I was surprised to see the stark ethnic identification differences between the two sub-groups. Whereas almost all of the Houston participants identified as Hispanic (and noted that their ethnicity “wasn’t really that important” to them), the San Diego participants overwhelmingly identified as Chicana or Mexican, not Mexican-American.<sup>7</sup> Perhaps this is not surprising, given San Diego’s proximity to the U.S/Mexican border, but I expected that there would have been more variation in the Houston participants’ identification. The fact that the Houston participants overwhelmingly identified as Hispanic and in some cases were offended when people would speak to them in Spanish is important for two reasons: it signals an both an apoliticization and depoliticization of their ethnic identity, and it is indicative of an almost complete assimilation into the dominant Anglo mainstream society (Johnson, 1997). Their identification with the term Hispanic—which is often disowned by Chicana feminist scholars because of its racist, Eurocentric implications (Martinez, 1998)—as well as their discursive and experiential distancing from traditional Mexican foods and music, is inextricably linked to their inability to speak Spanish fluently.

The Houston participants mentioned repeatedly that they could not speak Spanish, and some participants went as far as to say that they were not ashamed of this

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<sup>7</sup> It is perhaps not surprising that the San Diego participants overwhelmingly identified as Chicana or Mexican. Given that some of them had associates and bachelors degrees in Chicano Studies and that some of them had family members who were very active in the Chicano movement—a term largely used to describe the California version of the movement—they identified more with the term “Chicana” because it is a regional term. The term Chicano is not recognized or highly used in Houston or in other parts of Texas. In Texas, most members of the 1960s and 1970s Mexican rights movement (some of my older family members included) called it La Raza. Given Houston’s own involvement in fighting for Mexican and Mexican-American rights at the time, it was understood that Chicano was a California term, whereas Raza and Mexican were utilized more frequently in Texas.

and had no intention of ever learning their native tongue. Given that I have been working on growing my Spanish vocabulary in my later years and have been practicing my Spanish diligently, the repeated resurgence of this theme throughout the interviews caught me off-guard. This inability to speak the Spanish language could exist for various reasons: the participants' parents might not have been taught Spanish by their parents; the participants were not taught Spanish by their parents because they wanted them to "blend in" more easily at school; or perhaps, as it was in my family, Spanish might have been either eliminated from the home or spoken less than English because Spanish was banned from schools and children ran the risk of detention, suspension, or even expulsion if they were caught speaking Spanish on school grounds. In my mother's side of the family, she and her siblings were not allowed to speak Spanish at school because they would be suspended. Gloria Anzaldúa (2012) recalls what happened to her as a child at a school in south Texas when she was caught speaking Spanish: "It was good for three licks on the knuckles with a sharp ruler. . . 'If you want to be American, speak American. If you don't like it, to back to Mexico where you belong'" (p. 76). Ana Castillo (1994) describes Mexican-American women's Spanish-speaking (in)abilities as being a major component of the Mexican-American female's "schizophrenic-like existence" (p. 39). In addition to not being fully of Mexico or fully of America, Mexican-American women have Spanish-language schizophrenia for the following reasons:

She was educated in English and learned it is the only acceptable language in society. She may not be able to rid herself of an accent; society has denigrated

her first language. By the same token, women might also become anxious and self-conscious in later years if they have no or little facility in Spanish. (Castillo, 1994, p. 39)

Communication scholar Jacqueline M. Martinez (2000) elaborates upon this notion of language schizophrenia by noting that Spanish is the primary code through which one's Mexican ethnicness is performed and carried out. If Mexican-American women are distanced from their linguistic Spanish codes, Martinez (2000) asserts that they have internalized anglocentric, racist messages about their native tongue, their connection to cultural patterns and expressions carried out in Spanish is diminished, and they inevitably assimilate into mainstream Anglo-American culture.

Spanish-speaking schizophrenia and assimilation manifested itself most shockingly, however, in the Houston participants' retelling of their feelings and reactions when other Mexican/-American people would speak to them in Spanish. They repeatedly asserted that "Mexicans should speak Spanish because they're in *our* country" or "they're in America now, so they need to get with it." Perhaps entrenched in uncertainties about their ethnicity and Mexicanness being written upon their skin or their own insecurities about speaking Spanish, the Houston participants were adamant that Mexicans should "just suck it up and learn English already," not knowing whether or not people who spoke to them in Spanish spoke English as well. This interesting finding is indicative of what scholars call racist assimilation (Castillo, 1994; Johnson, 1997), meaning Mexican-Americans adopt dominant society's racial and racist attitudes toward other minorities, particularly other Mexicans. A racist-assimilationist culture discourages

men and women from recognizing how racist practices, like racial divides and stereotypes, function and instead perpetuates racial and ethnic divisions (Martinez, 2000). Once these racial divisions permeate social groups and cultural worlds, minorities are pitted against each other based upon racist norms and ideologies. Jacqueline Martinez (2000) notes, “As long as we remain locked within the social momentum of racist assimilation, we will live unconsciously within racialized designators supplied by that momentum” (p. 34), apoliticized Hispanic identification and Spanish-speaking inabilities functioning as two of those main racialized designators.

The notion that “*other* Mexicans need to speak Spanish” and the invocation of in-group stereotypes (such as when Lourdes noted that people at the grocery store speak Spanish to her because they probably think she’s “just another Mexican mom on welfare with a bunch of kids”) supports past studies that explore the functions of ethnic identity, particularly perceived ethnic identity in relation to other members of ethnic in-groups. For example, Doan and Stephan (2006) investigated why Hispanic people in New Mexico ethnically identify because they wanted to explore how ethnic identifiers relate to the notion of rewards and costs and hypothesized that Hispanic people would weigh the costs and rewards of various identities within certain contexts. They elaborated by noting that, “The functions of ethnic identity labels are important, in part, because they inform us about the ways that individuals’ self-attitudes and identities are used to bolster self-esteem, and conversely, are negatively affected by ethnic stereotyping, racism, and discrimination” (Doan & Stephen, 2006, p. 230). They found that their Mexican-origin participants overwhelmingly chose the term “Hispanic;” moreover, most participants

could not speak Spanish, recalled instances where other Hispanic people rejected them because of their Spanish-speaking inabilities, and even utilized negative ethnic stereotyping against other members of their in-group. Thus, the fact that the Houston participants also invoked stereotypes against “those Mexicans” not only supports past studies about ethnic identification, but it also points to insidious effects of racism and racist assimilation (Doan & Stephen, 2006).

Although the Houston participants overwhelmingly identified as Hispanic, the San Diego participants identified as Chicana and Mexican and were very vocal about their pride for their ethnicity. The interviews with the San Diego participants were embodied representations of and performances of their Mexican/Chicana identities as they performed past conversations between family members in both English and Spanish, reminisced about trips to México lindo, and vented about the difficulties associated with being a Mexican-American female in the U.S., such as their feelings of fitting in and never fitting in all at the same time, their pride for all things both Mexican and American, and their constant befuddlement with which box to choose on the Census. What became evident during the interviews was that San Diego participants had one fundamental identity component that the Houston participants lacked: a mestiza consciousness activated by their location near the border.

First coined by Gloria Anzaldúa in her highly influential book *Borderlands/La Frontera: The New Mestiza*, a mestiza consciousness occurs when Chicana/Mexican-American women gain a vastly different type of knowledge due to their living in between two countries, two cultures, and two different racial/ethnic ideologies. One

group's cultural, spiritual, and ethnic values are transferred to another, e.g. the combination of Catholicism and indigenous faiths or the combination of one's Mexican values with one's American values. This different type of knowledge is an "outsider within" status, which Cantú and Hurtado (2012) note gives Chicanas' "sense of self a layered complexity" (p 7). Living at the Mexican/U.S. border gives Chicanas/Mexican-American women a unique perspective on the socially constructed nature of identity categories: "By standing on the U.S. side of the river they saw Mexico and they saw home; by standing on the Mexican side of the border they saw the United States and they saw home. Yet, they were not really accepted on either side" (Cantú & Hurtado, 2012, p. 7). Bernadette Calafell (2004), a communication scholar, builds upon this notion of not quite fitting in one country or the other by asserting that Chicanos/Mexican-Americans "exist as both diasporic and nondiasporic citizens" (p. 177) because they live both within and outside of the Southwest, which was originally Mexican land, and their "homeland" might be both within the U.S. and across the border. As Gloria Anzaldúa (2009) notes, the Mexico/United States border is an important one not only because of the history between the two countries, but also because of how it metaphorically, symbolically, and literally becomes a site where "many different cultures touch each other," which leads to hybrid identities (p. 177). Although the hybrid identities might at first seem as irreconcilable identity fissures and disjunctures, the San Diego participants found ways to merge their American and Mexican selves.

Without my prompting, the San Diego participants spoke repeatedly about their mestiza consciousness (my terminology, not theirs) and how they constantly felt like

they were torn between two different worlds. Judith, for example, spoke in depth about how her entire life has been a struggle between her “Mexican self” and her “American self,” including the divides between her parenting styles, her professional identity, her career goals, and her food and music preferences:

Growing up, there was always this push about either you’re Mexican or there’s this other side, people who say you’re born in America and you eat hot dogs and stuff. I speak Spanish and eat cactus and bean burritos, for example. For many years, I was confused of which side I had to pick, which side I needed to pick. I eventually started embracing both worlds and I said to myself, I’m Mexican *and* American.

Judith elaborated upon her mestiza consciousness by describing to me how she eventually ended up reconciling these two complementary components of her identity, which is what Gloria Anzaldúa (2012) terms the *new mestiza*’s tolerance for ambiguities and contradictions: “I love living in San Diego because when my emotions are feeling unnurtured, I tap into my emotional state, cross the border to Tijuana, listen to Mexican music, and drink some tequila. Then I can put on my New Balance tennis shoes and enjoy the 4<sup>th</sup> of July. *It’s all about taking the best of both worlds and making it my own.*”

Just like Judith, Lara also described in depth how she always felt “split in two,” as if her Mexican side and American side pulled her in opposite directions. “Everyone picks on me because they say I’m ‘so Mexican.’ I’m Mexican *and* American. It’s just who I am,” said Lara. She explained, “I grew up with and respect both. Whenever I feel like I’m losing my Mexican roots, I just drive across the border for a few days to really

soak it all in. It's such a beautiful culture." Maria also felt the strain living as a Mexican-American here in the U.S. because she "always felt like I didn't quite fit in anywhere." As she recalled experiences from trying to fit in during her college years and trying to fit in at different jobs, Maria concluded, "You know, I just don't really fit in. I'm not American enough for the Americans, and I'm not Mexican enough for the Mexicans. That's why I just decided, I am who I am. I take something from both worlds." The experiences of these three participants, as well as those of the other San Diego participants, exemplify what Gloria Anzaldúa (2012) calls mental and physical neplantilism:

La mestiza is the product of the transfer of the cultural values of one group to another. She faces the dilemma of the mixed breed: which collectivity does the daughter of a darkskinned mother listen to? Cradled in one culture, sandwiched between two cultures, straddling all three cultures and their value systems, la mestiza undergoes a struggle of flesh, a struggle of borders, an inner war. (p. 100)

Throughout the interviews with the San Diego participants, it became clear that what helps them deal with the struggle of flesh, borders, and inconsistencies is a combination of the cultural values their parents instilled in them with their close proximity to the U.S./Mexico border. Despite all of the racial, ethnic, and cultural choques (cultural collisions) (Anzaldúa, 2012) they have experienced living as a Chicana/Mexican-American here in the United States, their ability to drive across the border whenever necessary solidified their strong identification with Mexico as both a



metaphorical and literal dual homeland. They learn to juggle their cultures and combine their American sides and their Mexican sides, their Mexican language, foods, and music with their American holidays, music, and clothing styles. As Medina (1998) notes, being a mestiza, a product of many cultures, allows the one to “stand at the crossroads where she can choose to balance the multiple and diverse cultures which inform her daily experiences and psyche” (p. 195). In order to create a synthesis of identities, dualities, and contradictions, one must not only be able to live in more than one culture, but she must also be able to create a way of live that transcends opposing dualities (Medina, 1998). The San Diego participants were able to transcend seemingly opposing Mexican and American dualities by eating and cooking both Mexican and American food, by speaking their Spanish fluently and by also teaching it to their children, by listening to both Mexican and American music, by having both white and Mexican friends, and by spending time in both Mexico and America.

In addition to constantly negotiating different explanations and performances of what it means to be a Hispanic, Chicana, or Mexican woman, the participants also negotiated the role of religion in their lives, as well as “who wears the pants” in their marriages. In terms of religion, one of the most fascinating findings is that certainly not all of the participants identified as Catholic, and those who did picked certain aspects of the Catholic faith to guide them through their everyday lives. This finding counters much academic scholarship that still stresses the extreme importance of Catholicism in Mexican-American women’s lives (Hunt & de Voogd, 2005) and supports scholarship that posits that Mexican-American women’s religious beliefs and practices to decline to

a certain extent with acculturation and are indeed negotiable and flexible (Atkin et al., 2008; Seth et al., 2011). Instead of adhering to Catholic mandates, participants appreciated the importance of Catholicism to their family and instead believed more in the *spirituality* associated with their faith, not so much organized religion itself. Participants believed in La Virgen de Guadalupe, prayed for protection, and believed in being a good person, yet they did not go through all of the Catholic sacraments, marry in the Church, go to mass every Sunday, or stray from birth control *just because* their religion tells them to do so. Moreover, the mestiza consciousness that some of the San Diego participants have made them aware of the patriarchal aspects of the Catholic faith, which resulted in them switching from Catholicism to variations of indigenous, Native American, and non-religion based spiritualities.

Finally, in terms of relational gender politics, participants had both negative and positive experiences with their spouses and relational partners. Although there was some evidence of male behaviors typically associated with machismo, such as infidelity and lack of communication, these experiences empowered participants to establish more egalitarian second marriages and have explicit conversations with their second husbands about what they expected from them and what they would not deal with. Moreover, there was also evidence of more positive aspects of machismo in the participants' marriages, such as equal partnerships, support for participants' career goals, and more help with childcare. These relational characteristics are indicative of the more positive characteristics of Mexican masculinity, such as honor, respect for others, support for the wife, and providing for the family (Pavich, 1986). These characteristics are part of the

other side of masculinity that is often discussed less in academic scholarship: caballerismo. The other side of hypermasculinity on the machismo dichotomy, caballerismo focuses on Mexican men's emotional connectedness with their wives and support of their families (Arciniega, Anderson, Tovar-Blank, & Tracey, 2008). It is also a more flexible, collaborative way of expressing one's masculinity in relationship to one's spouse (Torres, Solberg, & Carlstrom, 2002). This positive side of machismo not only presents a more complete conceptualization of Mexican men's masculinity, but it is also positively associated with one's ethnic identity and ability to engage in problem-solving with wives (Arciniega et al., 2008). Thus, the relationships that the Houston and San Diego participants had and currently have with spouses demonstrates how they negotiate power with their spouses and the various ways in which machismo manifests itself both positively and negatively in intimate relationships. Moreover, their relationships provide support for past research that suggests that negative machismo behaviors decline with acculturation and generational status (Hondagneu-Sotelo, 1992; Torres, Solberg, & Carlstrom, 2002).

In conclusion, this chapter has explored the various ethnic identifications, language abilities, religious preferences, and relational gender politics of Mexican-American women in San Diego and Houston. Contrary to popular characterizations of "the Mexican woman" and accompanying stereotypes (Andrade, 1982), this chapter is evidence of the fluid, constantly changing and negotiated ways in which Mexican American women perform and experience what it means to be a Hispanic/Chicana/Mexican woman in the U.S. These different ethnic identification

labels are very important to the women and are chosen over other labels because of family histories, Spanish-speaking (in)abilities, and a/politicization based upon where they live and whether or not they have a mestiza consciousness. Moreover, the participants also spoke of the various religious spiritualities they have and why they prefer spirituality over organized religion, as well as the different ways in which they negotiate power with spouses. This is but one snapshot of the heterogeneity of Mexican-American experiences, identity complexities, and different possibilities for describing, embodying, and performing the Mexican culture. Utilizing this as a starting point, the next chapter will explore how these participants experience prenatal screening and testing, as well as how their ethnic identification, religious preferences, and family members/spouses shape and affect that experience.

## CHAPTER V

### THE AMNIOCENTESIS REFUSAL

The technological revolution in reproduction is forcing us to confront the very meaning of motherhood, to examine the nature and origins of the mother-child bond, and to replace—or to let us think we can replace—chance with choice.

~Barbara Katz Rothman (1986), p. 115

The rise of reproductive technologies over the past three decades has undeniably changed women's pregnancy experiences. Now pregnant women have the ability to see their fetus via ultrasounds and test their fetus for chromosomal and genetic abnormalities via blood screenings and amniocenteses. It is widely accepted in feminist scholarship, communication scholarship, and medical scholarship that reproductive technologies have both benefits and burdens. Advantages of reproductive technologies include the possibility of improving fetal and maternal health and allowing pregnant women to prepare for their futures if they receive positive diagnoses for various birth defects (Rapp, 2000). Burdens associated with reproductive technologies, however, include risk of miscarriage, pregnancy complications, and the possibility of being presented with a difficult decision: pregnancy termination or life with a potentially disabled child (Hunt, de Voogd, & Castaneda, 2005; Katz Rothman, 1986; Rapp, 2000). This major life decision that women will go through during their pregnancies has been defined by feminist scholars as “the beginning of their ongoing activity of ‘doing motherhood’ in contemporary US society” (Markens, Browner, & Preloran, 2010, p. 50).

Women's experiences with reproductive technologies, particularly the amniocentesis procedures, have broadly been well documented. Barbara Katz Rothman's

foundational book *The tentative pregnancy: Amniocentesis and the sexual politics of motherhood* (1986), for example, explored how the amniocentesis procedure radically altered women's pregnancy experiences, as well as American cultural values associated with motherhood and disability. Building upon Katz Rothman's (1986) work, Rayna Rapp (2000) also explored the meaning of the amniocentesis procedure for American women and utilized an intersectional approach by interviewing Caucasian, black, and Latina women from a variety of class positions and educational backgrounds. Carole H. Browner and colleagues (1999; 2000; 2003) explored amniocentesis procedures for Mexican women and found that willingness to go through the amniocentesis procedure was affected by a variety of intertwined factors, including biomedical knowledge, lay knowledge, trust issues, translation issues, and relationships with providers.

Utilizing this scholarship as a platform for my dissertation, I became interested in trying to understand what role second- and third-generation Mexican-American women's generational status plays in their willingness to undergo the amniocentesis procedure, particularly as their generational status interacts with their perceptions of the relevance of Mexican cultural norms in their lives and their spousal relationships. Although Browner's scholarship (1999; 2000; 2003) has thoroughly researched the amniocentesis procedure for Mexican women, she interviewed Mexican women from Mexico or only explored their relationships with their physicians. Thus, I asked participants about their relationships with spouses, family members, physicians, *and* Mexican cultural norms to unpack the connections between and among these variables that shape whether or not Mexican-American women choose to undergo the

amniocentesis procedure. This chapter will discuss the three primary themes that emerged relating to the participants' perceptions of the amniocentesis procedure: refusal of the amniocentesis, religious and spiritual values, and conversations with family members.

### **The Amniocentesis: An Unnecessary Prenatal Test**

The first (and perhaps most telling) theme about Mexican-American women's relationship to the amniocentesis procedure is that they did want it or see a need for it. Out of 30 participants, only *one* underwent the amniocentesis procedure because of a significant medical issue during one of her pregnancies that highly influenced her to accept the amniocentesis so that she could "prepare for her baby's future". Other than that, the other 29 participants all refused the amniocentesis procedure during their pregnancies for a variety of reasons, and their religious, spiritual, and cultural values intertwined with their medical beliefs as reasons to reject the procedure. The three main reasons that participants refused the amniocentesis procedure is because they did not see a reason to undergo the procedure, they had no intention of aborting their babies, and thus they had no need for the amniocentesis test results.

### **"It Just Wasn't Necessary": No Reason for the Procedure**

The first reason that the participants rejected the amniocentesis procedure is that, at a very base level, they did think it was necessary. Only 4 participants had positive or ambiguous test results after their blood screening, and the other 26 participants had normal test results after their blood screening. As a result, the "normal" blood test results indicated to them that "they had nothing to worry about."

Isa, a 34-year-old mother of four from Houston, told me that the amniocentesis procedure “just wasn’t necessary because all the screenings came out fine. I might have at least kind of thought about the option of doing it if there was a problem, but since my blood tests were normal, I didn’t see a need for it.” Similarly, Nayara, a 33-year-old mother of four from Houston, stated: “I didn’t really see a need to go through with it because my blood test came back normal. I didn’t really see a need to go through with the amnio. It wasn’t a huge concern for me to do more tests.” Mireia, a 44-year-old mother of two from Houston, also shared Isa and Nayara’s sentiments: “I mean, we didn’t do the amnio stuff. Had there been issues that they’d found, I don’t know, maybe I would’ve considered it or maybe not. But since it didn’t really get to that point with either of my pregnancies, I didn’t see a need for it.”

Other participants also mentioned that they saw no need for the amniocentesis, and as conversations unfolded, they pointed to other structural factors such as the healthcare system, lack of insurance, and healthcare providers that also shaped their rejection of the amniocentesis procedure. For example, Evelia, a 32-year-old mother of two from San Diego, discussed how she had to go to a community clinic for low-income women for her prenatal care because she was a stay-at-home mom without insurance. Describing the clinic as “small, cramped, and low on time and resources,” Evelia noted that even though she would not have gone through the amniocentesis procedure anyway, the clinic might be one of the reasons why she was not offered the amniocentesis procedure in the first place: “Yeah, the other test came out okay. The doctor said I didn’t need the amnio because the blood screening was negative and that I didn’t need to go



that route. It was like a 2-minute conversation. In and out the door he went.” Marita, a 34-year-old mother of three, went to the same clinic as Evelia and mentioned that the doctors there did not offer the amniocentesis procedure to her:

I didn’t even know that the amnio was an option! It was my first child, I didn’t do that much research, and at the clinic, no one really told me anything about it. The clinic was always so packed with so many women needing to be seen, and the doctor would come in for like 5 seconds and then leave. Afterward, when I found out what the amnio was, there was no way that I was going to go through with that test! It just wasn’t necessary because my original blood scan came out okay. The doctor came in and said, “Your blood tests were negative” and that was it.

In addition to Evelia and Marita, Anita, a 32-year-old mother of 1 from San Diego, also went to a local neighborhood clinic because she did not have insurance. Anita described her local clinic with the same terms that Marita and Evelia used:

Yeah, it was just a mess. Not enough staff, too many patients. They didn’t even offer the amnio, they didn’t ask, nothing. I didn’t even know it was something that could be necessary. I don’t know if it’s because it’s one of those clinics where it’s low-income and for low-income people, so they didn’t offer much there. I wouldn’t have gotten it done, but they didn’t even offer it.

Thus, for some of the participants, the amniocentesis procedure was not a necessary prenatal test because the initial blood screenings were negative, meaning there was no indication of chromosomal or genetic abnormalities, and participants did not think it was

necessary to undergo more testing. However, as conversations progressed and narratives were recounted, it became clear that a variety of structural factors contributed to the participants' perceptions that the amniocentesis was not necessary. A handful of San Diego participants did not have insurance and as such went to community clinics for their prenatal care. With the participants' descriptions of low resources, overbooked patients, and overworked physicians, as well as the participants being uninsured, it is possible that these conditions contributed to the physicians telling the participants they did not need the amniocentesis or not even offering the procedure at all.

#### **“It Won’t Change the Outcome”: Intention to Keep the Pregnancy**

In addition to rejecting the amniocentesis procedure because they thought it was more unnecessary testing, participants from both Houston and San Diego also rejected the amniocentesis because they had no intention to abort their baby, regardless of any potential chromosomal or genetic abnormalities. Almost every participant said in some form or fashion that the amniocentesis “wouldn’t change the outcome” and that they had their mind made up since the beginning of their pregnancies. The participants were steadfast in their beliefs that they would not abort their baby (not their “fetus,” which is a key distinction that will be discussed later) because their baby was “a gift from God” and because they did not feel like Down syndrome or any other chromosomal condition would make their baby unhealthy.

First and foremost, participants mentioned that the amniocentesis was not necessary because they would not abort their babies who were “gifts from God.” Noelia, a 37-year-old mother of two from Houston, stated, “Whatever I get, I get, that’s what the

Lord is going to bless me with. We always live by that saying that God only gives you what you can handle, and my baby is a gift straight from the man upstairs!” Similar to Noelia, Yessica, a 33-year-old mother of two from Houston, situated her amniocentesis rejection within religious values:

I didn’t do the amnio because I was going to take what I can get. Whatever comes in my life, I’m going to take it regardless. I always think, let what comes, come. If that’s what God’s going to give me, then that’s what He’s going to give me. It wasn’t going to change the outcome. I would never abort my baby.

Ysabel, a 33-year-old mother of two from Houston, also noted that the amniocentesis would not change her mind about her pregnancy: “I didn’t do the amnio because it wasn’t going to change my way of thinking about having the baby. I didn’t really want to go that route because if my baby has something, then he has something. It wasn’t going to chance the outcome of my pregnancy or my love for my baby.” Dulce, a 34-year-old mother of two from Houston, also situated her rejection of the amniocentesis within her religious values:

I mean, I prayed about it and hoped to God that my baby would be okay, but it’s just like what they say, I guess. Mexican-American women, we have a big faith. Whatever God gives us, that’s what it is! It’s meant to be, you know? He’s giving it to me for a reason. That’s why I didn’t do the amnio. I was going to keep my baby regardless.

Thus, the influence of the participants’ religious and spiritual beliefs was an important component of their decision to reject the amniocentesis procedure.

In addition to the Houston participants, San Diego participants also shared this sentiment. Lara, a 32-year-old mother of two from San Diego, spoke of how her intentions to keep her pregnancy solidified her choice to reject the amniocentesis:

I think for me at that point, it was more that the outcome of the test wasn't going to change anything. I think there's some people who want the test because they think more about the quality of life of the child and they want to have the option of to terminate or not to terminate. For me, it didn't really matter what the outcome of the test was going to be because I was going to keep my baby and love it anyways, so why have somebody prick me in the stomach?

Esperanza, a 36-year-old mother of two from San Diego, also noted that the amniocentesis just was not necessary: "There was just no reason for it. I knew that whatever is going to come my way is going to come my way. The amnio test results wouldn't have changed my mind." Last, Beatriz, a 33-year-old mother of two from San Diego, encapsulated this theme perfectly when she noted: "I just didn't see the point in getting it done. It wouldn't have changed anything. It was just about me having my baby and that was it, you know? It's just that simple." Thus, participants overwhelmingly and repeatedly mentioned that the amniocentesis procedure was not necessary because they knew from the beginning of their pregnancies that they would not abort their babies, regardless of whatever conditions they might be born with. This conviction stemmed from their strong bond with the babies growing within their bellies and their religious values, from which they believed that their babies were gifts from God that they needed

to accept and love. Their bonds with their babies and their religious and spiritual beliefs were more important to them than any prenatal test and any possible birth defect.

In addition to their religious and spiritual beliefs, participants also discursively constructed new definitions of what it means for a baby to be healthy during their interviews. Participants argued that they would not abort their babies because they would still be healthy, regardless of any birth defect. For example, Nayara, a 33-year-old mother of four from Houston, told me that she went back and forth about whether or not rejecting the amniocentesis during her fourth pregnancy was a bad choice. However, after praying about it, she felt confident about her decision: “I prayed every day—did I make the right choice? I realized eventually that I did, though. I still would’ve had her. It wouldn’t have changed anything. As long as she was breathing, that’s all that mattered to me. She still would’ve been healthy.” This notion of the baby being healthy as long as s/he is breathing was also mentioned during Lourdes’ description of why she did not want the amniocentesis procedure. Lourdes, a 32-year-old mother of four from Houston, said she did not want the amniocentesis with her fourth pregnancy for reasons similar to Nayara:

I wasn’t even concerned with the outcome, you know? If they said, like, if a red flag was raised, I would’ve told them, “Okay, as long as it didn’t have to do with my baby biologically functioning or not existing or something, then why have [the amnio]?” As long as the baby is still breathing and the heart is still beating, then she’ll be okay and she’ll be healthy. As long as she’s okay, then that’s it.

In addition to Lourdes and Nayara, Dulce, a 34-year-old mother of two from Houston, situated her belief that babies with defects are still healthy within her lived experience of interacting with children who have Down syndrome: “I see a lot of Down syndrome kids that are talkative and normal. I also have a few friends with children who have Down syndrome, and you can’t even tell that anything’s wrong! They’re perfectly healthy. I didn’t really care about it. That’s why I didn’t do the amnio—it wasn’t going to change the outcome.” Yesenia, a 33-year-old mother of two from Houston, also mentioned her cousin with Down syndrome as a reason for believing that people with Down syndrome and other disabilities are still healthy:

If she was happy and breathing, then she was healthy and that was it. I didn’t do the amnio because I knew it wouldn’t change a thing. My cousin has Down syndrome and is perfectly normal! He went through high school with no issues and was even prom king. If my baby had Down syndrome, then she had Down syndrome. She would still be another happy, joyous, and healthy addition to our lives. We would’ve had her regardless. It wouldn’t have changed the way I love her.

Finally, Ysabel, a 33-year-old mother of two from Houston, also situated her belief that babies with defects are still healthy within her lived experience of being a mother to a first child with a disability: “I knew I didn’t want the amnio from the very beginning. I was just going to go with it and hope for the best. There was no point—I wasn’t going to NOT have my baby because of a disability. My first child has a disability and he’s perfectly healthy.”

Thus, participants overwhelmingly situated their rejection of the amniocentesis because they had no intentions of aborting their babies, and this was situated within a belief that a child with a genetic or chromosomal birth defect is still healthy. This belief stemmed from a variety of sociocultural and interpersonal influences, including their religious and spiritual beliefs and their experiences with other people who have Down syndrome. Since the participants already knew that they would not get an abortion, regardless of whatever genetic or chromosomal defect their children might have, then it was a logical next step that the participants saw no need for the amniocentesis test results.

#### **“What Would I Do with the Information?” No Need for the Amniocentesis Test Results**

Intertwined within interview discourses of pro-life, pro-disabilities, and religious values was the notion of information. Participants consistently noted during their interviews as they discussed their rejection of the amniocentesis that they did not know what they would do with the amniocentesis test results and thus realized that they did not need the amniocentesis. Participants weighed the pros and cons of the amniocentesis through deliberations about the utility of the genetic and chromosomal information that the amniocentesis test results could provide. Although this code shares many similarities with the two preceding codes, the key difference about this code is that the participants often construed the information that the amniocentesis could provide as a burden that they did not want. While some women would value this information as helpful for future planning purposes (i.e., preparation for a pregnancy termination or for a child with a

disability), the participants explicitly noted that this information would be burdensome because (1) it would not change their mind about the outcome of their pregnancies and (2) because it would stress them out and ruin their pregnancy experiences, which many described as a time in their life that was supposed to be joyous and calm. Flor, a 31-year-old mother of three from San Diego, said it best when she noted: “I didn’t not want the test, I knew I wouldn’t abort, so why would I even want that information in the first place?” Four participants *did* note that if their blood screenings came back positive, they might have considered the amniocentesis because they would have wanted the information so they could, as Mireia stated, “prepare for the future.” The other 26 participants, however, argued that “the information” (the amniocentesis test results) was unnecessary.

For example, Elena, a 39-year-old mother of one from San Diego, discussed with me at length during our conversation that her age was absolutely a worrisome factor during her pregnancy. She thought about the amniocentesis procedure for quite some time, yet finally decided against it, noting that the amniocentesis results would not affect her decision to keep her pregnancy:

The more I thought about the amnio, I thought, “Well, is it *really* going to change what I’m going to do later? Is it going to change anything right now? What am I going to do with that information?” I figured there was nothing I could really do with the information since it wouldn’t change my mind about whether to terminate the pregnancy or not. There was no point. There was no question about whether or not I was going to keep my baby, whatever the outcome might be.



Similar to Elena, Noelia, a 37-year-old mother of two from Houston, was also concerned about her age. She was 36 when she gave birth to her second child and also contemplated the amniocentesis procedure, given that her doctor reminded her about how her age could contribute to birth defects. She eventually decided against the procedure after weighing the advantages and disadvantages of the amniocentesis and the information it could provide:

You know, it's like nothing you can really prepare for when you're pregnant.

You take it when it comes. What I've come to learn is what happens when you get tested and then it's positive? You stress out about it and you become depressed and then you have complications during your pregnancy because of the stress. Why do that to yourself? Why would you even want the information? I know people do it to prepare themselves, but what's there to prepare for? You have to prepare for a child no matter what. I just kept thinking to myself, "What am I going to do with the information? What's it for?" There's just no point.

Elena and Noelia both decided against the amniocentesis because they knew that the test results would not change their minds about keeping their pregnancies. While it might seem obvious that a woman might not want the amniocentesis if her initial blood screening was negative, 3 of the 4 participants who *did* have positive blood screenings still decided to reject the amniocentesis procedure for the same reason: they knew that they test results would not change their decision to keep their pregnancies.

Dora, a 32-year-old mother of one from Houston, discussed with pain how her initial blood screening resulted in a positive test for Down syndrome. After creating an

initial wave of uncertainty and disbelief, she talked to family members, did some research, and found that blood screening test results and amniocentesis test results are not always 100% accurate. This realization was one of the main factors that contributed to her rejection of the amniocentesis procedure: “I also figured, what was I going to do with that information? You can choose not to go through with it, so why even go through all that? Why stress yourself out for your whole pregnancy if the results aren’t even 100% accurate? I wouldn’t have gotten an abortion anyways.” Eva, a 31-year-old mother of two from San Diego, also received a blood screening that was positive for Down syndrome, and she felt closure about the situation and the role of the test results after talking with her mother:

When I had a Down syndrome scare with the blood screening, I was so worried. The doctor kept telling me I still had time for an abortion, and I was like “What?!” I talked to my mom about it and I was trying to figure out whether to go through with the amnio or not. My mom said, “What are you going to do with that information? If you find out, you’d be about 5 or 6 months pregnant, and you still have 3 or 4 months to go. What would be your goal of getting those results?” That really helped me make up my mind. There was no reason for the amnio because I knew at the end of the day, it was still my baby. I didn’t need that information.

Thus, a majority of the participants rejected the amniocentesis procedure, whether they had positive or negative blood screenings. They did not think the amniocentesis was a necessary procedure because they knew that they would not abort their babies, and as

such, the information about their babies' genetic and chromosomal makeup that they could have received from the amniocentesis was deemed unnecessary. Associated with this domino effect of amniocentesis rejection reasoning were new conceptualizations of what it means for babies to be "healthy," as well as the advantages and disadvantages of health information and the role information played in their decision-making processes. Another type of information was also a key factor in the participants' rejection of the amniocentesis procedure: information from family members.

### **Conversations with Family Members: Family (Fear) Narratives & Family Social Support**

Various types of information can be sought to help people make sense of their health-related issues: information from websites and online social support groups, information from books and pamphlets, and interpersonal information from friends, family members, and other people in one's interpersonal network. Although 5 participants mentioned that they searched for information about prenatal testing on websites and phone applications and by reading the *What to Expect When You're Expecting* pregnancy book, 28 out of 30 participants stated that their main source of information regarding whether or not to undergo the amniocentesis procedure was their family. Participants spoke to their immediate and extended family members about the procedure, what it tests for, what it entails, and whether they should go through it or not. Even though 29 participants rejected the amniocentesis, almost each participant had a cousin who *did* go through the procedure, and these stories that were told to the

participants chained together to create an overarching narrative: that of the false positive amniocentesis.

**“My Cousin Had the Test Done and Got a False Positive”: Risk, Complications, and Family Fear Narratives**

Riddled with fear, pain, terrible experiences, false positives, and directives to ultimately reject the amniocentesis, these family fear narratives scared participants to varying degrees and greatly influenced participants to not go through with the amniocentesis. Participants’ madres, primas, and tías constantly recounted stories of what happened when other family members went through the amniocentesis procedure and had a terrible experience. To the participants’ knowledge, none of their mothers went through the amniocentesis, some for religious reasons and some because of the decade in which they gave birth (1970s and early 1980s). The family fear narratives surfaced in almost every interview, and the participants’ main take-away message from their family members’ experiences—mostly their cousins—was that they needed to stay away from the test because it will more than likely result in a false positive.

For one segment of participants, hearing their family members’ experiences did not necessarily incite fear in them, but it *did* make them question the utility and accuracy of the amniocentesis. Estrella, a 44-year-old mother of two from Houston, noted that she did look online for certain prenatal testing information, but she also talked to her cousins because “it was information I could *really* trust”: “Yeah, I talked to my cousins about [the test] a lot. Two of my cousins got positive testing that their baby would possibly have Down syndrome, but they were born perfectly fine. I talked to them about the

possibility of false positives.” Marisa, a 34-year-old mother of two from San Diego, also mentioned that her cousin’s experience made her doubt the amniocentesis procedure’s accuracy: “When my cousin was 38, she did the amnio because her doctor really pushed the test. They told her that her baby had Down syndrome, and her baby was born perfectly fine! She was so stressed through her pregnancy that she didn’t even get to enjoy it. That’s why I didn’t want the amnio—I just don’t think it’s always right.”

Nayara, a 33-year-old mother of four from Houston, spoke to her cousin about her experiences with the amniocentesis, and Nayara said she did not want a false positive like her cousin: “When she gave birth to another little girl, she had a false positive earlier on Down syndrome, so she worried her whole pregnancy and told me not to do it. I didn’t want that to happen to me.” Last, Dulce, a 34-year-old mother of two from Houston, spoke about her cousin’s “sad, sad” experience and how it influenced her to reject the amniocentesis:

I told my husband regardless of what the screening results were, we were NOT going to do the test. We were just going to roll the dice and see what happens.

My cousin did the amnio, and they told her that her son was going to have Down syndrome. They told her that she was within the time to have an abortion, and she chose not to. Her baby came out perfectly healthy! I would be devastated if I had to end my pregnancy and my baby was fine!

Thus, for some of the participants, their cousins’ experiences of constantly receiving false positives were enough to convince them to reject the amniocentesis. For other participants, however, their cousins’ experiences consisted of a fear progression that

started with amniotic fluid leakages and ended with stories of miscarriages and stillborn births; these narratives scared participants away from the amniocentesis and ultimately convinced them to reject the test.

Dora, a 32-year-old mother of one from Houston, recounted the stories her family told her about their amniocentesis experiences and said the stories scared her: “Once I told my family I was pregnant, everyone started telling me NOT to do the test because of my other family members who had false predictions and other issues. They kept telling me, ‘Why would you want to do that? You know your cousin did the test and started leaking fluid!’ It made me feel horrible. They scared me out of it.” Lara, a 32-year-old mother of two from San Diego, also had a cousin who had amniotic fluid leakage after her amniocentesis:

Plus, when my cousin did her amniocentesis, about a week after that her amniotic fluid dropped dramatically. She was probably at like 5% or something like that, so she had to be delivered earlier. Her daughter was a preemie because of that. I think the family experience with the amnio made me not want to do it with my children. It really scared me. The less intervention in my body, the better. The more interventions that you have, the more you risk.

Beatriz, a 33-year-old mother of two from San Diego, mentioned that her main fear after talking to family members was that the amniocentesis would poke the baby: “All my aunts would tell me not to get the test with the needle because of the risks associated with it. They told me about how it could poke the baby and how that happened to my

cousin. What if nothing was wrong and they ended up poking my baby? That's why I didn't do it."

In addition to amniotic fluid leakages and the possibility of poking the baby, another amniocentesis risk that surfaced in family narratives was the possibility of having a miscarriage or a stillborn birth. Marita, a 34-year-old mother of three from San Diego, noted how many of her family members had complications with the amniocentesis, including miscarriages: "I didn't want to do the amnio because of the risk. I was so scared of what could happen. I know you can have internal bleeding, loss of the baby, early birth, stuff like that. I have a few family members who lost their babies or had premature births, and I didn't want to expose myself to that." Elena, a 39-year-old mother of one from San Diego, had both a friend and family member who had miscarriages after their amniocenteses: "Both of them went through it, and both got Down syndrome diagnoses. My cousin ended up having a late-term miscarriage, and the other one had a false diagnosis and her baby was fine. Having that information, I was both floored and terrified." Lara mentioned that she rejected the amniocentesis because her brother's girlfriend had a miscarriage after her amniocentesis:

I refused it, no questions asked, because I did not want anything that was associated with a higher risk of miscarriages. I did not want to take that chance whatsoever. My brother's girlfriend got pregnant right before me, had the amnio, and then had a miscarriage. Seeing her go through that really freaked me out. I didn't want to risk anything remotely that could affect my pregnancy.

Finally, Nayara told her cousin's amniocentesis story during her interview, which resulted in a stillborn birth:

Well, my cousin had an amniocentesis and then her baby was born stillborn.

With my third and fourth children, I read up on it more, and because my cousin had a stillborn, I did more research and talked to more people. I found out about all these false positives and thought, "Nope, I don't want to worry." And my cousin, when she told me what she went through, I thought, "Nope, definitely not." With her stillborn, she had the amnio done, but they poked the baby. The baby was poked! That's another reason I didn't want it.

Thus, as participants reached out to their family members for information about the amniocentesis procedure and to learn about how their cousins experienced the amniocentesis, they heard narratives about false positives, pregnancy complications, risks, miscarriages, and stillborn births. Their family knowledge complemented the medical knowledge the participants' obtained about risk and potential amniocentesis complications, and the family narratives were an integral component of their rejection decision. Another set of family conversations went hand-in-hand with the family fear narratives to influence participants' decision-making: family social support conversations.

### **"If My Baby Had a Problem, I Know My Family Would Help": Family Social Support**

As participants told family cuentos about their cousins' amniocentesis experiences, they spoke in the same breath about how their family would support them



and their children, regardless of any birth defects. Closely linked to family fear narratives, conversations about family social support also influenced participants' refusal to undergo the amniocentesis procedure. Most of the participants' mothers and spouses, as well as their extended family members, told them that they would be there to help the participants and offer support and other resources if their children had any birth defects.

First and foremost, participants spoke broadly about how their family support was “a given” and that they had nothing to worry about, regardless of any chromosomal or genetic birth defect that their babies might be born with. Dulce, a 34-year-old mother of two from Houston, spoke about how she knew she would be “fine,” thanks to her family support: “We know that our extended family is going to help us. It’s just that that’s a given. So whether my children would’ve come out with Down syndrome or whatever, we would’ve been fine.” Dora, a 32-year-old mother of one from Houston, also spoke about her appreciation of her family’s support: “Even though they kind of scared me out of the test in the first place, my husband’s family and my family kept telling me that even if the baby had Down syndrome or something else, it was *our* baby and that was it. I knew the entire family would be there to help up.” Other participants described their family support as a family philosophy, a family value, and an unspoken family rule. Sandra, a 36-year-old mother of two from San Diego, described her tight-knit family as having a “certain kind of family philosophy”: “I had a lot of family discussions about the amnio, and it’s more of our family philosophy that having a baby with a health issue just isn’t that big of a deal. It’s not that important to us. If anything like that were to come our way, we’d be able to deal with it as a family and support each

other.” Similar to Sandra, Flor, a 31-year-old mother of three from San Diego, spoke about her family’s support as an “unspoken rule”: “It’s kind of an unspoken rule in our family. I didn’t really need the test because I knew that my family members and I all felt the same way—that the test wouldn’t matter either way because we wouldn’t get an abortion and because we would all be there to help out no matter what.”

In addition to speaking about family support more broadly, participants also recalled conversations they had with their mothers and spouses about family support within the context of whether or not to undergo the amniocentesis procedure. Noelia, a 37-year-old mother of two from Houston, spoke to her mom about the amniocentesis, and this was her mom’s response: “I talked with my mom about it, and she told me, ‘Why do you need that test? ¿Pa’ qué? You know we’re going to be here to help you through it, whether your baby has something or not.’” This conversation, according to Noelia, made her more comfortable rejecting the amniocentesis because she said she knew her family would be there for her. Just like Noelia, Yesenia, a 33-year-old mother of two from Houston, felt that her mother’s support was integral to her prenatal testing experiences, considering she had a Down syndrome scare with one of her blood screenings:

Why would I need that test anyway? I knew for a fact that my mom and the rest of my family members would help us out if our daughter was born with something. We’re such a close family, and both my mom *and* my husband went to each doctor’s appointment. I knew that we would be okay regardless. My mom kept saying, “It’s our baby. It’s our family baby, and we’re going to love her

regardless of what could be wrong with her.” An amnio wouldn’t change how we loved her.

Most of the participants’ mothers played important support roles for their daughters as they decided to whether or not to undergo the amniocentesis. Participants mentioned that their mothers would be there to offer emotional, financial, and mental support.

Spouses also played a supportive role for the participants within the context of reproductive decision-making. Although 5 participants mentioned that their husbands told them making a decision about prenatal testing was a “woman’s thing”—thus gendering prenatal testing and putting the onus of the responsibility on the female—25 participants mentioned that their husbands were “incredibly supportive” of their decision-making processes and the possibility that they might have a child with Down syndrome or something else. When Yessica, a 33-year-old mother of two from Houston, went to her doctor’s appointment to discuss the amniocentesis, her husband accompanied her. When her doctor asked her about the amniocentesis, her husband immediately spoke up and said they did not want the test, even though they had not previously discussed whether or not to go through with the amniocentesis. Yessica mentioned that her husband’s outcry startled her doctor and prompted her doctor to repeatedly ask *her* if she wanted the test or not. Although this could be construed as a controlling husband silencing his wife at the doctor’s office, Yessica said this was a consciousness moment for her because she realized at the doctor’s office that this moment was indicative of her husband’s support for their child and any sort of birth defect that might occur. Thus, Yessica said, “I knew in that moment I didn’t need it

because of my family's support. Once my husband was set that he didn't want it and I knew I had his support, plus the fact that my extended family would help out regardless, I knew I could do it. I had their support, so I figured let's go with it."

Other husbands showed their support by simply saying, "I support you" and by doing their own research about their wives' pregnancies. Lara, a 32-year-old mother of two from San Diego, said she frequently spoke with her husband about prenatal testing: "I kept talking about whether or not to do the amnio with my husband, and he reassured me that no matter what happened, we would love our baby no matter what. His support really meant a lot to me. He was so supportive of what I wanted to do with my body, and he said, 'If it makes you more comfortable to not go through with it, don't. I support you.'" Juanita, a 32-year-old mother of one from San Diego, also described her partner as being supportive: "My partner was so, so supportive. He would always tell me, 'You're fine. We're fine. Our baby is fine.'" Maria, a 40-year-old mother of two from San Diego, spoke about how her husband was "in for the long haul":

My husband was already in for it. Even though he and I did not plan at all for our first one, he said he wanted our baby, no matter what. He was already supporting it, and our mothers and families were supporting it. So, you know, regardless, we were going to keep our baby, no matter what she may have had. That made me feel wonderful.

Last, Anita, a 32-year-old mother of one from San Diego, spoke of her husband's support through the lens of him doing research: "He was very involved in everything! He did his own research and always let me know that everything was about me. He was

so supportive and let me know that regardless of whatever may happen to our baby, it wouldn't matter. He would say our baby was our little one." Thus, participants overwhelmingly mentioned their family's social support as another factor that contributed to their rejection of the amniocentesis procedure. Participants rooted their family's social support within notions of "family values" and "unspoken family rules," and the two most frequently discussed types of familial social support included their mothers and their spouses. Closely linked to the familial support was another value rooted within their culture and their relationships with their family members: their religious and spiritual values.

### **Religious & Spiritual Values**

The third and final component that influenced participants' refusal of the amniocentesis was their religious and spiritual values. Although research consistently points to the strong influence of the Catholic religion in Mexican-American women's health decision-making (Gallo et al, 2009; see Vidal-Ortiz, 2010 for a review), participants expressed their religions and spiritualities as affecting their amniocentesis decision-making on a spectrum, with highly religious participants on one end and less religious participants on the other end. The key to determining the role of their religion in their amniocentesis decision-making was the salience of their religion to their identity and their family identity.

#### **"Prayers are More Powerful than Any Sort of Testing": Direct Religious Influence**

Ten of the participants described their religious beliefs as directly influencing their decision to reject the amniocentesis. This segment of the participants strongly

identified with their various religions and argued that their religious beliefs made them stronger and more confident about their pregnancies. Noelia, a 37-year-old mother of two from Houston, spoke during her interview about how she and her second husband are “very religious.” Because she has endometriosis, she and her husband did not think she would be able to conceive; she said they prayed a lot for a baby, and they conceived two weeks after their wedding. She attributed her ability to conceive to her prayers and her religion:

Oh, we’re very, very Catholic. I wanted to make sure that we did everything right this time. We even waited until we were married! Being Catholic is important to us, and in terms of pregnancies, whatever I get, I get. That’s what the Lord is going to bless me with. We always live by that saying that God only gives you what you can handle. Our baby is a blessing, regardless of what she might have been born with.

Dora, a 32-year-old mother of one from Houston, strongly identifies as Baptist and also discussed her religious beliefs as affecting her decision to reject the amniocentesis: “I chose not to do the amnio because whatever my baby was or had, if that’s the way God wanted it, that’s the way it was going to happen. I wasn’t going to try to sit there and fix things, and I certainly wasn’t going to have an abortion because I don’t believe in that.”

Flor, a 31-year-old mother of three from San Diego, spoke during her interview about how her pro-life values stem directly from her Christian upbringing and religious practices: “We were raised Christian, and the way we were brought up, getting an abortion was never even an option. It was just, ‘Oh, you’re pregnant! You’re going to

have a baby!’ That’s it. In our family, we’re blessed to have babies. Babies are a blessing. That’s another reason why the test was unnecessary.” Maria, a 40-year-old mother of two from San Diego, went back and forth during her interview about her religious affiliation and the salience of the Catholic faith in her life, yet finally decided that her Catholic religion and Catholic-inspired family values were important to her and influenced her decision to reject the amniocentesis:

Under so many eyes, you accept a family member no matter how it may come to be, so that was one of the reasons I was like, ‘I don’t need the test. It’s God’s will to receive this child.’ It could also be because of my mother’s upbringing because she comes from a very strict Catholic family where they believe you have as many kids as the good Lord will send you. Whatever the Lord sends you and however the Lord sends you your children, you cherish them and bring them up in the Lord’s way.

Last, Yessica, a 33-year-old mother of two from Houston, noted that her strong Baptist faith made her stronger and more confident about her pregnancy and her ability to deal with any kind of health issue:

I didn’t do the amnio because I was going to take what I can get. Whatever came in my life, I was going to take it regardless. I thought, let what comes, come. If that’s what God’s going to give me, then that’s what he’s going to give me. It wasn’t going to change the outcome. During my whole pregnancy, I prayed that my babies would be healthy. Plus, it was about the confidence that I know that once I pray, God will help me throughout the pregnancy and throughout the

development of the baby. Prayers are more powerful than any sort of testing or anything like that. It's more about a relationship you have with God.

Thus, for this segment of the participants, their religious identification was an important component within their prenatal decision-making encounters. Participants described the explicit aspects of their religious beliefs that influenced their decision to reject the amniocentesis, including their pro-life values, their faith that God would take care of them through any problem, and their confidence that God would support them and strengthen them. During other parts of their interviews and also in passing, participants noted that God would never send them anything they could not handle, and a child with a disability was part of their logic. Many of them felt that if it was God's will for them to have a child with a disability, that He would also help them, whether it was through family support or other means. It is not surprising that this segment of the participants was the same group who had strong religious affiliations and identities. The other segment of the participants may not have had supported organized religion as strongly as this particular segment of the participants, but they overwhelmingly admitted that it was difficult for them to draw the line between the organized religion they grew up with and their current religious/spiritual beliefs.

#### **“It Could’ve Been Because of My Religion, But...”: Indirect Religious Influence**

While some of the participants spoke proudly of their religious affiliations and their religious beliefs, other participants seemed bewildered and sometimes confused when discussing their relationships with organized religions and how their religious beliefs may or may not have contributed to their amniocentesis refusals. This segment of



the participants overwhelmingly mentioned in some form or fashion during their interviews that “I was raised X religion, but I’m not anymore,” yet as their narratives and justifications progressed, they encountered difficulties trying to communicate the relationship between their organized religions, their lingering religious and spiritual beliefs, and their amniocentesis refusals.

Lourdes, a 32-year-old mother of four from Houston, spoke during our interview conversation about how she considered herself to be more spiritual than religious. As the conversation unfolded, it became clear that the relationship between her spiritual beliefs and her organized religion affiliations was more muddled than she originally thought:

Well then, I guess with that being said, it *is* in the religion, in my religion, not to have an abortion, and so it’s just, well, yeah, but that didn’t even play a part in my decision. It’s just what I believe in personally. I wouldn’t—checking the amniotic fluid is just something I didn’t want to do because it wouldn’t affect anything. Yeah, I guess, religion does play a part in it. I’m Pentecostal, and of course they don’t condone abortions, so... I don’t know. It wasn’t a big issue. It wasn’t something that the pastor pushed, you know? So I guess it played a role, but I don’t know.

The communicative “back and forth” between religion, spirituality, and the amniocentesis procedure was also present in other interviews. Similar to other participants, Dora, a 32-year-old mother of one from Houston, introduced the role of the pastor and the organized church in her explanation of why her organized religion was not an important factor in her amniocentesis refusal:

I never took my religion into consideration about it. I thought more, like, my religion would come into effect in terms of whether I would have my baby or not. As far as the test, that never came up. I never thought about it that way. I never thought, “Well, what would my church do? What would my pastor do?” You know what I mean? I never thought about it that way... I mean, now that I think about it, maybe the religion did affect it. It’s hard to tell!

Just as Lourdes and Dora rationalized the relationship between organized religion and the amniocentesis by introducing church figureheads and the actual Church itself, other participants introduced their role within the Church as they made sense of how their religion may or may not have affected their decision to reject the amniocentesis.

Ysabel, a 33-year-old mother of two from Houston, was unsure about how her religion contributed to her amniocentesis refusal: “No, I don't think my religion had anything to do with it. Maybe it did because I don't believe in abortion and I don't believe in any of that, so maybe my faith could have contributed a little bit... but not explicitly.” Yesenia, a 33-year-old mother of two from Houston, received a positive diagnosis for Down syndrome when she went through the blood screening with her second pregnancy. When asked about whether her religious affiliation contributed to her amniocentesis refusal, she immediately said no, yet backtracked and eventually decided “it might have”:

It *could* be because both of us are Catholic. Both of us are somewhat active in our church, so it could've been. But at that moment, we weren't really putting it on faith to be like, “Look, this is what we believe.” It was more about whether or

not [the amnio] was the right or wrong thing to do. I mean, it *could* be because both of us were raised in the Catholic tradition, so it was like, “That’s wrong,” but who’s to say? It’s kind of already implanted in us that having abortion is wrong. We just knew that going in and poking her wasn’t the right thing to do.

Beatriz, a 33-year-old mother of two from San Diego, spoke at great lengths during her interview about her conflicted perceptions of religion and her “on-and-off” relationship with the Catholic Church. She mentioned that this “on-and-off” religious relationship troubled her, yet she concluded that her religious and spiritual beliefs were still an important part of her amniocentesis refusal:

I grew up Catholic, so those Catholic values are still there, but I don’t know how much I still practice the religion or identify with it. I guess a lot of those religious beliefs are there because that’s how I was raised. I guess with all the testing, like no matter if he’s going to have whatever he’s going to have, I’ll still have him. I think maybe that *does* have to do with religion, with God sending me this baby for whatever reason and that’s what I’m getting. No matter if something’s wrong with my baby, I’m still going to keep it because God decided to give him to me.

Finally, Elena, a 39-year-old mother of one from San Diego, encapsulated this segment’s experiences with organized religion, religious beliefs, and the amniocentesis procedure when she described her perceptions of religion and medical decision-making:

My mom is still very Catholic, my family is still very Catholic, and I would have to say that even though I’m not really a good practicing Catholic, all those values and morals are still in me, whether I want them or not! They’ve been ingrained

for so long. I'm not saying it's a bad thing or it's a good thing. They're there, and as far as an amnio or abortion, that wasn't even on my radar. I would have never considered that.

Thus, for this segment of the participants, the lines between organized religion, religious affiliation, religious beliefs, and the rejection of the amniocentesis procedure were messy and murky at best. Although participants initially asserted that their religion had no influence on their amniocentesis refusal whatsoever, the opportunity to talk through their religious affiliations and religious beliefs helped them realize that the two are not easily separated. Even though these participants noted that they are not as religious as they used to be and that most of them had separated themselves from organized religion in someway, they all agreed that their religious and spiritual beliefs—being pro-life, viewing pregnancies as gifts from God, not condoning abortion for reasons pertaining to morality and ethics—were still ingrained within them and indirectly contributed to their refusal of the amniocentesis procedure.

#### **“No, My Religion Had Nothing to Do With It”: No Religious Influence**

The final segment of the participants noted that their religious beliefs did not matter within this context because they viewed the amniocentesis as a medical decision, not a religious decision, and discursively constructed the amniocentesis as a stressful event that was to be avoided at all costs because of potential complications and risks.

Estrella, a 44-year-old mother of two from Houston, spoke during her interview about her gestational diabetes and other health issues she had during her pregnancies. For her, each prenatal decision was constructed and defined as a medical issue, not a

religious issue that required consultation with a priest or other religious members: “Um, nope, my religion didn’t have anything to do with it at all. Being Catholic, no, it didn’t even cross my mind. It’s not like I asked my priest about it. I see the amnio more as a medical issue than anything.” Maura, a 32-year-old mother of two from Houston, had a prior miscarriage and gestational diabetes, so she made sure that she did not add any additional complications to her current pregnancy: “No, my religious beliefs didn’t play a role in me not getting the test done. Yeah, I’m a Christian and I go to church, but my pregnancy wasn’t about that. It was about me not doing anything during my pregnancy that could cause me to lose my baby.” Mireia, a 44-year-old mother of two from Houston, had extreme birthing complications and extra surgeries with her first pregnancy that resulted in a two-month postpartum hospital stay. Those complications framed her second pregnancy in medical terms, not religious terms:

No, the religion itself didn’t play a role in me rejecting the amnio. After everything I went through with my first pregnancy and birth, I just wanted to survive this one. It wasn’t about religion. It was about preventing additional complications that could be caused by the amnio. I think you have to have extremely strong religious beliefs to let that affect what you’re going to do with your child or unborn child, and even though my husband and I are Catholic, we definitely don’t have extremely strong religious beliefs.

Paula, a 33-year-old mother of two from Houston, had eye complications when she was born that have lasted through her adult life. She said her religion did not play a role because she was more interested in “more physical things like my baby’s health”: “Some

of my religious values were still there, but the actual religion itself didn't really take any part in my decision to not do the testing. I was worried about the risks. Plus, I knew the amnio couldn't test for my eye problem, so what's the point?" Finally, Nayara, a 33-year-old mother of four from Houston, described herself as somewhat religious, yet also noted that her religious beliefs did not affect her decision. She spoke about medical outcomes of prenatal testing and was more concerned about the amount of stress that would affect her pregnancy experience: "My actual organized religion didn't really play a role, no. It was more of how much did I want to stress during my pregnancy. It wasn't a religious decision for me." Thus, this last segment of the participants noted that their religious affiliations and beliefs did not contribute to their decision to refuse the amniocentesis procedure. For them, the amniocentesis decision was not situated within notions of abortion, morality, ethics, or religion; rather, it was situated within medical notions of risk, complications, stress, and doubts about the amniocentesis procedure's ability to accurately test for a variety of chromosomal and genetic anomalies.

### **Discussion: Toward a "Homegrown" Understanding of the Amniocentesis Refusal**

This chapter has sought to join a conversation that is central to health communication and feminist debates about reproductive technologies: the social construction of prenatal testing for Mexican-American women. Although scholars in both fields have studied the social construction of the amniocentesis procedure for Caucasian women, African-American women, and Latina women (Katz Rothman, 1986; Rapp, 2000), few scholars have explored the social construction of the amniocentesis procedure for Mexican-American women.

Carole Browner and H. Mabel Preloran, two of the main scholars who research how Mexican women perceive and utilize prenatal testing, have found that the majority of Mexican-origin women accept the amniocentesis procedure (Browner, Preloran, & Cox, 1999; Markens, Browner, & Preloran, 2003); that those who refuse do so because of skepticism toward doctors and trust in experiential knowledge sources (Markens, Browner, & Preloran, 2003); that “less acculturated Mexican women” are more likely to reject the test (Browner & Press, 1995); that there is a significant relationship between their positive perceptions of doctors’ recommendations and their acceptance of the amniocentesis (Browner, Preloran, & Cox, 1999); that they often believe that a negative test result would provide reassurance (Browner, Preloran, & Cox, 1999); that they sometimes find the amniocentesis “frightening” (Browner, Preloran, & Cox, 1999); and that they typically make the decision to refuse or accept the test alone, although spouses occasionally contribute (Browner & Preloran, 1999; Browner, Preloran, & Cox, 1999).

Despite these findings, however, detailed discussions of social and cultural factors were oftentimes not included in the aforementioned research designs: Mexican-origin women accepted the test at comparable rates, but why? What factors supported and encouraged this decision? Is this finding relevant to second- and third-generation Mexican-American women? What were the roles of generational status, family members, religious/spiritual beliefs, and spouses in their prenatal testing decision-making, as well as the relationships between and among these sociocultural factors? What other factors might contribute to Mexican-American women’s acceptance or rejection of the amniocentesis?

Contrary to some of the aforementioned findings, 29 of 30 participants overwhelmingly refused to undergo an amniocentesis, and the themes that emerged during the interviews created what the participants thought were fairly logical and straightforward thought processes for the amniocentesis rejection: the participants knew before the medical appointment that they would reject the amniocentesis because it would not change their intentions to keep their pregnancies, because their family would support them and help them if their babies were born with a chromosomal or genetic issue, and because their varying religious and spiritual beliefs taught them to value life and their children's lives, regardless of the circumstances. These reasons are undoubtedly situated within a larger web of sociocultural factors, including their family relationships; their views of life, death, morality, and ethics; their perceptions of prenatal risk that are supported by family narratives and experiences, yet sometimes go against medical discourses of prenatal and genetic risks; and their support of disabled children and the possibility of having a disabled child. This combination of sociocultural factors constructs what I am referring to as a "homegrown understanding"<sup>8</sup> of the participants' refusal of the amniocentesis procedure, which goes against some previous findings that oversimplify Mexican-American women's experiences with prenatal testing.

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<sup>8</sup> In her book *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*, Rayna Rapp (2000) deployed the terms "homegrown epidemiology" and "homegrown statistics" to refer to the various ways in which minority women make sense of medical discourses about prenatal risk, as well as the ways in which they evaluate this information within their own "homegrown" understandings and constructions of prenatal risk as evidenced by their family members' experiences. A key example of this terminology is represented by Mireia when she stated, "Yeah, the doctors tell me that I'm in my 40s and at much higher risk. But so many of my aunts and cousins had babies at late ages and their babies were fine. I don't think I have anything to worry about."



The first theme that emerged from interviews centered upon their perception of the amniocentesis procedure as a test that is unnecessary for two main reasons: the test would not change their intention to keep their pregnancies, and as such, there was no need for the information that the amniocentesis procedure could provide. Within this theme are many important discourses central to prenatal testing: the viability of the amniocentesis procedure; the role of health information within reproductive contexts; and ultimately, the relationships between and among prenatal testing, abortion rights, and disability rights. Although research suggests that Mexican women undergo the amniocentesis procedure at rates comparable to Caucasian women (Hunt & de Voogd, 2005; Browner & Press, 1995) and that they think amniocentesis results could make them feel more comfortable and reassured during their pregnancies (Browner, Preloran, & Cox, 1999), the participants in this study argued the exact opposite: that the test was unnecessary, the results were unnecessary, and the test seemed frightening and stressful.

A key factor that contributed to the participants' perception of the test being unnecessary was their conceptualization of what it means for a baby to be healthy. In every interview, participants consistently referred to their pregnancies as their "babies;" not a single participant referred to their pregnancy as "the fetus" or "my fetus." This is significant within the contexts of reproductive politics and prenatal testing because it radically altered the ways in which the participants viewed their entire pregnancies and created a very specific starting point from which they viewed prenatal testing. Participants noted that each time they underwent a blood test or an ultrasound, they were not testing or looking at a fetus or a "clump of cells"—they were very clear that they

were looking at their babies, babies that they were excited about, babies that their extended family members were expecting, and babies that they had been planning for.

Related to this notion is what the participants viewed as “healthy,” as most of them noted that their babies (not fetuses) would still be healthy if they had Down syndrome or spina bifida. A few of the participants had previous children with disabilities (autism and kidney issues), and other participants had family members or friends with Down syndrome. Participants relied on these experiential knowledge bases as they explained during interviews that children with genetic issues are still healthy, functioning individuals in society and as such, they noted that as long as their babies were breathing and moving, they were healthy. As Rayna Rapp (2000) has noted, the “choice” any woman makes to accept or refuse the test flows from “the way that both pregnancy and disability are embedded in personal and collective values and judgments within which her own life has developed” (p. 91). Although research suggests that women’s positive attitudes toward disabilities in the context of prenatal testing might change once they receive positive prenatal test results (Press, Browner, Tran, Morton, and Le Master, 1998), this finding was not supported with this participant group. There was no “provisional normalcy” with these participants: they supported the rights of disabled children to be born, and they would not abort their babies, regardless of any genetic issue.

The second theme that arose during interviews was the importance of the family unit in helping participants solidify their decision to reject the amniocentesis. Although research suggests that Mexican-origin women often make their amniocentesis decisions

alone (Browner & Preloran, 1999; Browner, Preloran, & Cox, 1999), this finding was not supported with this group of participants. Rather, familismo was an important component of the participants' decision-making process because the majority of the participants relied heavily upon their family members for advice, support, strength, and guidance. The strong influence of family members within this context, however, is a double-edged sword: although family members provided emotional, mental, and sometimes financial support to participants and constantly reassured them that they would be there to help with their babies, especially if their babies were born with a genetic issue, family members also sometimes scared participants out of the amniocentesis because of their past experiences.

Participants' immediate and extended family members became an important source of health information seeking within the prenatal testing context, as participants looked more toward family for amniocentesis advice and information and less toward physicians, books, and websites. As sources of prenatal testing health information, family members' narratives about their own prenatal testing experiences created an extremely powerful message source that persuaded participants to reject the amniocentesis. Some family members spoke of their own abilities to produce healthy babies, despite their late age ("My cousin was in her late 30s and had a perfectly healthy baby, so I knew I could do the same"), and other family members spoke about their "terrifying" and "traumatic" experiences with the amniocentesis test.

Laden with notions of risk, pain, stress, and false positives, family members discursively constructed the amniocentesis procedure as a test that rarely yields accurate

results. Given these two important sources of “homegrown experiential knowledge” (see Rapp, 2000), participants felt empowered that their bodies would produce healthy babies and also felt troubled at the thought of the amniocentesis poking their baby or yielding inaccurate test results. Moreover, participants were also confident that their family members would be there to support them if they had a child with a disability, and they had no doubts that a child with a disability would “fit perfectly” into their family and be welcomed. Rayna Rapp (2000) found that working-class Latinas living in the U.S. were concerned with the impact of disabled children on their family members’ needs, goals, and aspirations. With both the working-class and middle-class participants in this study, there was no concern with a disabled child detrimentally affecting other family members; rather, participants were confident that their family members would provide important mental, financial, and emotional resources, as well as accept a disabled child as “one of their own.”

The finding that family members are extremely important health information and support sources for Mexican women is certainly not new. What *is* new, however, is the fact that this finding applies to second- and third-generation Mexican-American women. Scholars have consistently found that Mexican women often rely on their family members as support sources and sources of experiential knowledge. For example, Galvez (2011; 2012) conducted an ethnographic study of how Mexican immigrant patients experience their pregnancies here in the U.S. and found that they subscribed to their own personal and preconceived notions about the potential risks associated with their pregnancies. Galvez (2012) noted that “the vast majority of women reported that

their mothers and grandmothers (and sometimes their sisters and the women themselves) delivered babies without complications in settings far more technologically primitive” (p. 41) Participants in her study refused the amniocentesis because few—if any—of their family members had babies with chromosomal problems and were confident in their bodies’ ability to produce healthy babies.

Although scholars argue that Mexican women’s ties to their family and cultural norms diminish with acculturation (Browner & Press, 1995), my results do not support this finding. Rather, the family unit emerged as a powerful support group *and* information-seeking source, and it undoubtedly influenced the participants’ decisions to refuse the amniocentesis. The participants drew upon their more localized and experiential knowledge sources to decline the amniocentesis, which was shaped by what Markens, Browner, and Preloran (2003) refer to as “alternate and less medicalized” frameworks for understanding their pregnancies (p. 51).

The third and final theme that emerged was the role of the participants’ religion in contributing to their decision to decline the amniocentesis. The fatalistic, Catholic, self-sacrificing Mexican woman is one of the most essentialized and overly simplistic constructions of Mexican women, and this construction often factors into both healthcare interactions and health policy. As Segura and de la Torre (1999) have noted, however, this image is highly problematic:

We contend that the ideological “presence” of the self-sacrificing Chicana/Mexicana martyr-mother within Chicano/Mexicano family research lays a foundation for much of the way health care services and delivery are

constructed. This stereotype interjects itself into acculturation frameworks, obscuring the complexity of gender as a social construction among Chicanas/Mexicanas in favor of a static moment in a population's history and culture. (p. 156)

La sufrida, as Segura and de la Torre (1999) call her, is a one-dimensional construct of Mexicana identity that encompasses a set of "idealized" and "feminized" characteristics. A few of these characteristics include being very holy and very, very religious. This notion, which proliferates academic and medical discourses about Mexican women and their health, was not supported by this group of participants. Although some participants were indeed very religious, not all participants were Catholic and not all of the participants viewed their religious beliefs as a key factor in their decision to reject the amniocentesis. Rather, the participants described their religious beliefs as falling on a spectrum, with highly identified religious affiliations on one end and no religious affiliation on the other end.

The more important factor here, however, was not necessarily their religious affiliations, but more so their religious and spiritual beliefs that were ingrained in them by family members at a very early age. Although some participants have distanced from organized religion in their older years, their reproductive decision-making was influenced to varying degrees by a multitude of religious and spiritual beliefs, including the notion that life is sacred, the rejection of abortion, the acceptance of every family member, and divine intervention from God ("It's God's will to receive this child" and "God decided to give him to me"). As Rayna Rapp (2000) has noted, the relationship

between science, risk, and religion is “both deeply intertwined and open to interpretation when viewed through the eyes of individual pregnant women” (p. 158). It would be overly simplistic and essentializing to assume that a Mexican-American woman would reject the amniocentesis procedure *solely* because she is Catholic. As the participants noted, their religious beliefs were a factor, but they were not the sole factor that contributed to their rejection of the amniocentesis procedure. My findings support those from other scholars who have found that Mexican-American women view their religion in pragmatic terms. Markens, Browner, and Preloran (2010) found that their Catholic participants were very pragmatic about how their religion permeates society, their culture, and their own actions. Moreover, identifying as Catholic was not a strong predictor of their amniocentesis decision-making (Markens, Browner, & Preloran, 2010). Rather, their participants evaluated the role of their religion along with their medical information and their perceptions of risk. Similarly, the participants in this study spent a great deal of time evaluating organized religion, the role of religion in their lives, and both the direct and indirect influence of their religious beliefs on their reproductive decision-making.

Thus, the decision to refuse the amniocentesis was undoubtedly as much a social decision as it was a medical decision (Katz Rothman, 1986; Rapp, 2000). Influenced by family members, spouses, religious beliefs, and localized/experiential conceptualizations of risk, the participants ultimately decided that the amniocentesis was an unnecessary procedure. Family members and religious/spiritual beliefs surfaced as highly influential components of the reproductive decision-making process because they empowered

women to refuse the amniocentesis. Although the participants' rejection of the amniocentesis procedure could be coded as yet another example of *religiosidad* or *fatalismo*—meaning that participants were succumbing to their religion and fate at the expense of the material effects of potentially having a child with a disability—I argue that it is representative of high levels of participant agency within the reproductive decision-making process. A few participants mentioned that they were unsure about their decision to decline the amniocentesis; the majority of the participants, however, were confident that they made the right decision, and almost all of the participants decided in the early stages of their pregnancy that they were going to reject the amniocentesis.

Participants pragmatically weighed the effects of having a disabled child on their lifestyles, work schedules, and family members, yet reached two important conclusions: 1) that their babies would be healthy as long as they were “breathing” and “biologically functioning,” and 2) their family members formed a strong support unit that would help them and welcome their babies. Moreover, participants weighed genetic information about diagnoses and risks with localized, experiential knowledge about how risk and complications factor in with their homegrown knowledge about their family members' reproductive histories. Participants ultimately decided that the amniocentesis was an unnecessary procedure because they would not have an abortion if the test results were positive, and they evaluated multiple information sources and social influences throughout the process.

This decision-making process is evidence of what feminist scholars have referred



to as “active engagement” with reproductive technologies. Instead of being compliant subjects within the medicalization of childbirth, women are increasingly becoming active participants within their reproductive healthcare as they evaluate medicalization, risk, complications, and the necessity of various prenatal tests (Fordyce & Maraesa, 2012). While the participants in this study did not necessarily reject biomedical reproductive care as an entire enterprise, they selected the tests that they perceived to be most valuable (Browner, 2012). What emerged as one of the most interesting components of this segment of the interviews was that while participants rejected the amniocentesis procedure, they wholeheartedly accepted blood screenings and ultrasounds. This presents a bit of a contradiction, given that they adamantly opposed the amniocentesis procedure, yet the participants readily accepted blood screenings for four reasons: (1) they repeatedly mentioned that a negative blood screen result meant their children would be fine; (2) if anything was wrong with their child, they would find the anomaly during the ultrasounds; (3) they were under the assumption that the blood screenings and the ultrasounds were mandatory tests, whereas the amniocentesis was an optional procedure; and (4) the blood screenings and ultrasounds were less invasive and had lower associated risks. The amniocentesis, on the other hand, due to its ethical implications, perceived complications, and invasive nature, was perceived as unnecessary and not always accurate. As Fordyce and Maraesa (2012) have noted, “women often exhibit particular strategies of engagement with available medical practices, using them creatively as well as actively to reflect on individual choice and in consideration of sociocultural constructs” (p. 7). In this study, participants were not

“docile recipients of statistical risk categories,” but rather “pragmatic actors” who made reproductive testing decisions based upon family values, religious beliefs, and personal and cultural interpretations of health and risk.

In conclusion, the participants not only had a homegrown understanding of the amniocentesis that was influenced by their personal experiences, perceptions of risk, and relationships with family members, but it was also influenced by their interpretations of medical and scientific information. Many participants noted that they “had nothing to worry about” because of negative blood screenings or that they *were* worried because of positive blood screenings, and both indicate incorrect perceptions of what the blood tests actually screen for. Moreover, participants were also highly influenced by their family members’ experiences with the amniocentesis procedure, particularly by their family members’ false positive experiences. Although the amniocentesis procedure false positive rate is estimated to be 5% (Benn, 2002; Spencer, Spencer, Power, Dawson, & Nicolaides, 2003), participants perceived that the amniocentesis false positive rate is much higher. Due to all of these factors, participants chose the blood screenings and the ultrasounds instead of the amniocentesis, and the next chapter will discuss the final component of the participants’ reproductive decision-making grid: their relationships with their healthcare providers.

## CHAPTER VI

### RELATIONSHIPS WITH HEALTHCARE PROVIDERS

The traditional doctor-patient relationship is rapidly changing, especially in the field of genetic testing. “The doctor knows best” and the blindly trusting patient are no longer ideals. Instead, the expectation lies in the development of partnerships aimed at allowing patients to make informed decisions. But acting as partners demands mutual knowledge and trust and solid communication that is sometimes difficult to achieve.

~ Browner and colleagues (2003), p. 1942

Women’s relationships with their healthcare providers are a very important component of their reproductive healthcare, particularly as it relates to prenatal screening and testing. Given the ethical and moral implications of prenatal testing and the decisions that must occur after positive diagnoses, scholars have recently advocated for the practice of shared decision-making between patients and healthcare providers about the various screenings and tests that could occur during a woman’s pregnancy.

Shared decision-making is a communicative task that draws upon notions of informed consent and informed choice to ensure that patients are well educated about the screening and test options and alternatives so that they can make the best, most informed decision possible (Charles et al., 1997; Charles et al., 1999). As I have mentioned in earlier chapters, shared decision-making has four key characteristics: (1) it involves at least two participants, such as the patient and physician; (2) both parties participate in the decision-making process; (3) information sharing about options and alternatives is a necessary prerequisite; and (4) a treatment decision is made upon which both parties agree and with which both parties are satisfied (Charles et al., 1997, pp. 685-688). Moreover, scholars have noted that this process should occur in a trusting and

comfortable environment where both parties exchanges information and expresses their preferences (Charles et al., 1999; Epstein & Street, 2007). Thus, given the paucity of research that explores decision-making processes between Mexican-American women and their physicians about prenatal testing, this chapter explores the (sometimes not so) shared decision-making processes between the participants and their physicians, as well as the positive and negative aspects of their relationships with their healthcare providers. While every participant saw an OB/GYN for at least one of their pregnancies, ten participants saw midwives in conjunction with their OB/GYNS, ten participants saw high-risk doctors because of their gestational diabetes, and one saw an acupuncturist in conjunction with her midwife and OB/GYN. Interviews with participants about their relationships with their healthcare providers revealed three main themes: the physicians' role in the amniocentesis decision, satisfactory relationships with healthcare providers and unsatisfactory relationships with healthcare providers. Overall, most participants engaged in shared decision-making with their healthcare providers when they rejected the amniocentesis and appreciated their physicians' caring and informative communicative styles; however, in some instances, participants noted that their physicians either did not offer the test at all or pressured them about the test, and they described their physicians' communicative styles as rough, impersonal, and characterized by incomplete explanations due to time constraints.

### **Physicians' Role in the Amniocentesis Decision**

The first theme that emerged was the role of the participants' healthcare providers in their amniocentesis decision-making processes. For the most part,

participants engaged in shared decision-making with their physicians when they discussed whether or not to undergo the amniocentesis procedure. Most participants described the conversation with their physicians about the amniocentesis as “just another standard conversation” during their prenatal care, one that was a “fairly easygoing” and “didn’t take too much time.” Given that most of the participants knew at the outset of their pregnancy that they would not terminate their pregnancies regardless of any birth defect or genetic anomaly, it is not surprising that this conversation was constructed as a routine meeting. However, a few participants noted that this conversation with their physicians pressured them and made them feel uncomfortable, whereas seven participants noted that at least one of their physicians during one of their multiple pregnancies did not offer the procedure at all.

#### **“I Just Went with the Flow”: Reciprocal Communication**

The majority of the participants described their conversations with their physicians about the amniocentesis as “supportive,” “easy,” and as “not trying to influence [their] decision one way or another.” One of the tenets of shared decision-making about healthcare issues is that physicians and participants both share information and preferences about the treatment or test, and that the final decision is one that is satisfactory to both parties involved. For the most part, participants noted that their physicians briefly explained what the amniocentesis entailed, the participants mentioned that they did not want the procedure, and, as Nayara mentioned, “that was it!”

For example, when Nayara, a 33-year-old mother of four from Houston, spoke about her first doctor, she stated, “When we spoke about the amnio, it was a really easy

conversation. The doctor told me about the test and what it tested for, and I already knew I didn't want it, so I told her that I wasn't interested. That was it!" Maura, a 32-year-old mother of one from Houston, also described this conversation as a "that was it!" type of encounter: "With my doctor, she just told me what the amniocentesis was and asked if I wanted it. I told her no and then I left!" Similar to Nayara and Maura, Flor, a 31-year-old mother of three from San Diego, spoke about her amniocentesis conversation with her doctor as "quick and understanding":

I didn't do any of the genetic testing either, and I think also because my doctor was Asian and older, their culture is kind of similar to ours in the sense that they're really family-oriented, so he didn't push it. I said it wasn't going to make a difference, that I wasn't going to terminate the pregnancy either way, and he didn't push it. He offered it, I gave my explanation, and he said, 'Yes, I understand.' That was that. We started talking about other things after that.

Lourdes, a 32-year-old mother of four from Houston, discussed how she had the same OB/GYN for all four of her pregnancies and that the conversation was "low stress." When remembering how the first discussion about amniocentesis went, she recalled that, "He brought it up, explained it well, and answered my questions in a way that I could understand. I told him with my first one that I didn't want the amnio, and that was it. With my second one, he just reminded me what the process was, and with my third and fourth pregnancies, he said, 'I'm sure you remember!'" Last, Elena, a 39-year-old mother of one from San Diego, stated that her conversation with her physician about the amniocentesis was "very easygoing": The doctor brought it up as an option for me and

gave me a lot of information about it. I asked him if he thought I needed it and he said no because my blood tests and ultrasounds were all normal. Since I didn't want to do it and he said he didn't think it was necessary, I didn't go through with it. It was a very easygoing conversation."

In addition to describing the amniocentesis conversation as easygoing and low-stress, participants also mentioned two other important facets of their amniocentesis conversations with their physicians: their appreciation of the information the physicians gave them about what the amniocentesis entails, and their appreciation of their physicians' supportive nature when they refused the amniocentesis procedure.

First, participants consistently mentioned that they appreciated when their physicians would "take the time to explain" what the amniocentesis entailed and whether, in their professional opinion, they thought it was necessary. For example, Dulce, a 34-year-old mother of two from Houston, described how she felt well informed because of her doctors' explanations:

They introduced the tests and stuff probably at 2 months in. They *did* explain to me that they were going to do the sugar screening, the blood screening for Down Syndrome, and that the amniocentesis would be an option. That's what I was told at first. They told me that if everything came back negative, they wouldn't go any further, but if something came back positive, then they would go in and take out fluid *if* I wanted to. They also told me that there could be risks for the baby. I was very well informed. It made me feel comfortable and reassured.

Yessica, a 33-year-old mother of two from Houston, also described how she felt well informed about the amniocentesis procedure: “It was really easy having the conversation about prenatal testing with my doctor and nurse practitioner. The nurse practitioner explained really well what the test was. I was thankful for that.” Finally, Noelia, a 37-year-old mother of two from Houston, stated that her healthcare provider was “very helpful” when she described the amniocentesis procedure to her: “My doctor brought it up, but we said no because we were going to take our baby as it came. She asked me if I wanted to do it and I said no because it didn’t really matter. She was really helpful, though! Really helpful... She explained it and I told her no. She just wanted to make sure I knew about all my options.”

Secondly, participants consistently mentioned that they were appreciative of their physicians’ support for their decision to reject the amniocentesis. Beatriz, a 33-year-old mother of two from San Diego, had midwives and OB/GYNs during both of her pregnancies. She noted that she preferred her midwives to her physicians because of their “mother-figure” support:

I asked both of my midwives during my two pregnancies if [the amnio] was something I needed to do, and both of them said I really didn’t have to. I could just kind of feel in both of them that it was something I didn’t really have to do. They didn’t give me that vibe. It felt like it would be okay if I didn’t. That’s why I chose midwives—I felt like they would care more about me and be more of a mother-figure type of thin. They said, ‘It’s not something that has to be done. You don’t have to do it if you don’t want to.’ I’m really thankful they put it like



that.

Lourdes, a 32-year-old mother of two from Houston, also spoke of her physician's support when she decided to not undergo the amniocentesis procedure: "When we talked about the amnio, he said a lot of women don't do it and that the test is just to help you, to let you see if you're going to want to keep the baby. He just said what it does, that a lot of women don't do it, and that I didn't have to do it if I didn't want to. He was very supportive of what I wanted to do." Finally, Dora, a 32-year-old mother of one from Houston, mentioned that she valued her physician's honesty about the amniocentesis and how she did not try to sway her decision:

What I really liked about the doctor was that once I told her I wasn't going to go through with the testing, she didn't try to talk me into it. She wasn't like, 'You really should have it.' She was like, 'If that's what you want to do, then that's what we'll do.' She was very reassuring about my decision, and I liked that. You know most doctors are probably like, 'Do the test, do the test!' She wasn't like that. she was like, 'I understand that you don't want to do the test, and I'm totally fine with that.' She was very honest about the risks and issues, and she wasn't trying to sway me either way. I really liked that.

Thus, for this segment of the participants, shared decision-making occurred between them and their healthcare providers as they discussed whether or not to undergo the amniocentesis procedure. Given the invasive and particularly risky aspect of the amniocentesis procedure, participants were satisfied with their physicians' information giving and explanations of what the procedure entails; moreover, they appreciated that

their physicians did not attempt to sway their decision in either direction. Doctors and patients were engaged in the decision-making process and the physician accommodated the patients' wishes, so shared decision-making occurred with the physician accommodating the patients' choice. A smaller segment of the participants, however, recalled experiences where their doctors pressured them to consider the amniocentesis, and this created stressful and dissatisfying moments within their patient-provider relationships.

#### **“He Just Wouldn’t Lay Off!”: Pressure to Consider the Amniocentesis Procedure**

Seven of the participants recalled moments during at least one of their pregnancies when their physicians pressured them to consider the amniocentesis procedure. As I mentioned in the previous chapter, almost every participant decided during the early stages of her pregnancy that the amniocentesis procedure was not an option because they would not terminate their pregnancies. Thus, when their physicians constantly brought up the amniocentesis as a topic of conversation, even after they already disclosed that they did not want it, participants became resentful and irritated.

Flor, a 31-year-old mother of three from San Diego, spoke about her irritation due to her doctor’s “pushy nature”:

She asked me more than just a couple of times, “Are you sure you don't want it? Are you *really* sure?” It wasn’t just because of my nephew with Down Syndrome, but because of some of my other family members who’ve had children with birth defects. She asked me again, “Are you sure you don’t want the amnio because of the cases in your family?” After I said no, she even brought

out her chart and started discussing Down syndrome rates with me. I just kept telling her, “No, no no.” It irritated me! I don’t know if it’s because of the insurance and they wanted to get more testing in or if it was a personal belief of the doctor or her culture.

Lara also spoke about how irritated she was when she “kept going back and forth” with her doctor about how she did not want the amniocentesis. Lara, a 32-year-old mother of two from San Diego, is a military wife; she had her first child with military insurance in a civilian region with civilian providers and her second child with military insurance in a military region, meaning it was mandatory for her to visit the base hospital for all of her prenatal needs during her second pregnancy. When discussing the differences between her civilian physician and her military physician, she concluded that she preferred her civilian doctor for the following reason:

You know what was surprising? My first doctor didn’t push at all. As far as the military doctors were concerned, they were like, “Well, why *don’t* you want the amniocentesis? I can’t understand why you wouldn’t want it. I think it’s something you should really consider.” They were way more pushy about me getting the amnio done because they really wanted me to go through with it, and I wasn’t risking it. That’s what I told them. I just had to keep telling them that I didn’t want it. I don’t know if it’s a military sort of thing or what, but they were very adamant about it.

Dora, a 32-year-old mother of one from Houston, is also a military wife; however, she preferred her military doctors instead of her civilian doctors because her civilian doctors

were “pushy and annoying”:

My other doctor said, “Well, it’s *your* baby, but I really think you should go through with the amniocentesis. When it’s your first child, you should want to do those kinds of tests. Don’t you want to know? I think you should really consider it.” I was like, “What? What are you talking about?” Whatever. I didn’t understand why it mattered so much to her. I kept telling her I didn’t want it! I hated that she kept pushing it on my and making me feel guilty for not wanting it.

In this instance, Dora was unhappy with her doctor because she was “pushing her beliefs” about the amniocentesis procedure during the encounter, even though Dora repeatedly told her doctor she did not want the test. I cannot say with certainty why the doctor adamantly supported the test, but despite the doctor’s intentions, Dora was dissatisfied with this encounter and with her physician.

The sentiment of being irritated with their physicians’ “pushy” natures was compounded when participants received positive results that indicated a higher probability of Down’s syndrome. In two of the more extreme cases, Yesenia and Eva recounted their mental and emotional distress that they attributed to both their physicians’ “heartless” delivery of bad news and “pushy” nature when they suggested the amniocentesis procedure. Yesenia, a 33-year-old mother of two from Houston, gave birth to her second child when she was 32. During her pregnancy, she found out that one of her blood screenings tested positive for Down syndrome. After discussing the amniocentesis procedure with her husband, they decided against it and opted instead for the ultrasounds. Yesenia recalled the ultrasounds as “being normal” and expressed her

bewilderment with the entire process:

We took the test that measured her head, her arms, everything to see how her bone structure was coming along, and that's how they could tell if she was going to have Down syndrome. They measured her head, her jaw, every single bone they could find. Everything came out normal, yet they still said, 'Well, you still have that chromosome. All her bone structures are okay, and there's no shorter bones like Down syndrome children have. Everything looks regular.

Yesenia said that at point, she was relieved and happy, yet the conversation "took a turn for the worst" at that point:

*Then* they said, "But we can go in with a long needle, poke the sac, get her fluid, and test it." By this point, I thought, "Wait a minute. I'm so far along!" They said, "There's still a chance that you could lose her." I kept saying no, I didn't want it, but they kept trying to talk us into it! The doctor said, "Well, you know it's very hard having a Down syndrome baby." I said no because my cousin has Down syndrome and he's perfectly normal, so we didn't care. The doctor kept trying to persuade us and said, "Well, if your daughter does have Down syndrome, there's still places where you can give her up for adoption. It's *your* decision in the end." He was so heartless. I can't believe he said those things! He was even drawing out chromosomes!

Within this encounter, at a very base level, Yesenia is interacting with her physician and discussing the amniocentesis procedure. The doctor explains the procedure, Yesenia expresses her preferences, and the doctor expresses his preferences about the test.

Another reading of this interaction, however, shows the doctor interjecting with his (perhaps unsolicited) opinions about the difficulties associated with birthing and parenting a child with Down syndrome. Whether his intentions were positive or negative (acting with his patients in mind or showing his biases toward children with disabilities), Yesenia concluded that her doctor was “out of line” during this encounter.

Eva, a 31-year-old mother of two from San Diego, also had a dissatisfying experience with her physician when he broke the bad news, so to speak, about the possibility of her second son having Down syndrome. Eva mentioned that the physician found a hole in her son’s heart during an ultrasound and that this key piece of information created a convoluted, uncomfortable encounter between her and the physician:

The doctor came back and said so nonchalantly, “You know, we found this thing on his heart, and it’s not really that big of a deal. But your kid might have Down syndrome.” He was so chill about it! He was so calm. I just started crying when he said that. I don’t know how many women he’s had to tell that to, and then it got me—was I going to look into things further? Would that lead to something else? Then he said, “Don’t worry, you can still have an abortion. We can do the amniocentesis to find out.” I said no, and he kept pushing it, saying it was a good idea, that it would help me prepare for the future, that I would be more educated.

I kept saying no, and he just wouldn’t lay off. After that, I switched doctors.

Just as Yesenia felt her physician was out of line when he told her she give up her child for adoption, Eva was offended when her physician told her she still had time for an abortion. Even though the physicians might have encouraged the amniocentesis

procedure so the participants would be more informed and might have mentioned the abortion and adoption alternatives so that the participants would be aware of all of their available options, this segment of the participants felt irritated and offended when their physicians “wouldn’t take no for an answer.” In these experiences, both the physician and patient were engaged, but there was tension because the physician was not very accommodating. In these scenarios, the shared decision-making was a bit rough because of the process of needing to resolve both parties’ opinions.

### **“My Doctor Didn’t Even Offer It to Me!”: No Mention of the Amniocentesis**

#### **Procedure**

Finally, eight participants mentioned that at least one of their physicians during their multiple pregnancies did not mention the amniocentesis procedure nor offer it as a prenatal testing option. A few participants noted that they were unaware of the amniocentesis procedure and “weren’t too worried about [not being offered] it”, whereas other participants attributed the lack of a conversation about the amniocentesis to negative blood screening results and time constraints.

Anita, a 32-year-old mother of one from San Diego, noted that her doctor did not offer the amniocentesis procedure to her and speculated as to whether it was because of the clinic or the physician’s beliefs: “I didn’t go through the amnio because the doctor didn’t even offer it. He didn’t offer it, he didn’t ask, nothing. I didn’t even know it was something that was necessary. I didn’t know that much about it. I don’t know if it’s because it’s one of those types of clinics where it’s low-income and for low-income people or because he doesn’t support the test, but they didn’t offer much there.” Maria, a

40-year-old mother of two from San Diego, said that not being offered the amniocentesis “didn’t really bother [her]”: “My doctor didn’t offer it. I guess because they did ask if I had any family members with disabilities. To my knowledge, I don’t think I have any, so I assume they were fine. That was pretty much it! I wasn’t too worried about it. It didn’t really bother me.”

In addition to participants mentioning that they were not bothered because their physicians did not offer the amniocentesis, a few participants concluded that their physicians did not mention the amniocentesis procedure because of their negative blood screening results. Isa, a 32-year-old mother of four from Houston, responded with shock when I asked her about whether she discussed the amniocentesis with her doctor. After a few moments, she answered, “Wait, they didn’t even offer me the test! Maybe it’s because my blood test results were normal? You know, I’m actually not sure.” Juana, a 32-year-old mother of one from San Diego, also seemed a bit puzzled when asked about her amniocentesis conversation with her physician. She said, “You know what? My doctor never even offered me the needle procedure. They just offered me the blood work. That was it. Maybe it’s because my blood test came back okay?” Marita, a 34-year-old mother of three from San Diego, spoke of this phenomenon with ease as she mentioned, “With my third pregnancy, my doctor didn’t offer it because everything was fine. We did the blood tests and the ultrasounds, and everything came back negative. That was it.” Esperanza, a 36-year-old mother of three from San Diego, also noted that her doctor did not offer the amniocentesis to her because of a combination of her negative blood screenings and his “high-tech equipment”:



Well, my doctor did the blood test, but he didn't even offer the amnio to me. He was a specialist and had very high-tech ultrasound machines. Everything was very advanced. Everything was so normal, aside from my blood sugar, and he didn't make a big deal about it. There was never anything wrong with the ultrasounds, so I think that was why. I had quite a few ultrasounds because of my gestational diabetes and my previous miscarriages.

Last, Dulce, a 34-year-old mother of two from Houston, realized that her doctors did not offer the amniocentesis when she was pregnant with her second son and attributed this omission to the doctors' lack of time during their medical encounters:

Well, now that you mention it, I wasn't offered that during my second pregnancy. I knew about it and I got the blood work done, but I wasn't told anything about the taking of the fluid if the tests came back positive. The OB/GYN I had for my second pregnancy, he was just like [snapping fingers], "Here's what's going on and here's what we're going to do." He asked me if I had any questions, but he was *really* like, "I'm on a time frame here, so let's hurry it on up. Let's go. Let's get this rolling." He didn't even bring up the amniocentesis! It's probably because he didn't have any time for it.

In this scenario, Dulce notes that she was very aware of her doctor's stressed and time-conflicted nature. She stated earlier in her interview that this doctor in particular was always rushing their appointments, perhaps because he had "too many patients and too little time." Even though her doctor asked her if she had any questions, Dulce interpreted his rushed manner as conveying that he did not have time to listen to her questions and

give her answers, nor to explain the amniocentesis, which could potentially be a long and detailed conversation.

Thus, for this smaller segment of the participants, their physicians did not offer the amniocentesis to them as a prenatal testing option. Most of them were not too terribly bothered by this omission and attributed their lack of conversation about the amniocentesis procedure to their negative blood screening results and physicians' time constraints.

Overall, most participants engaged in shared decision-making with their physicians when they decided to refuse undergoing the amniocentesis procedure. Both parties shared information and preferences and ultimately reached a decision that was satisfactory to both the participants and their physicians. Although a few participants felt pressured by their physicians and other participants' physicians did not offer the amniocentesis as an option, most participants were fairly satisfied with their physicians. The next two themes focus on the participants' relationships with their physicians and the positive and negative aspects of their physicians' communication during their prenatal care.

### **Satisfactory Relationships with Healthcare Providers**

As participants recalled whether or not they discussed the amniocentesis procedure with their physicians, their memories of that specific encounter evolved into conversations about their relationships with their physicians and their preferences for their physicians' communication styles and skills. During these conversations, I posed the question, "How were your relationships with your physicians during your prenatal

care?” Participants overwhelmingly pointed to two key and often intertwined facets of their physicians’ communication that were either very successful or very unsuccessful, according to the participants’ preferences and recollections: the physicians’ caring communication style and the physicians’ open lines of communication, which was evidenced by their information exchange and their listening skills.

### **“I Felt like I Was Talking to a Family Member”: The Caring/Personalismo Communicative Style**

The first aspect of their physicians’ communication that participants repeatedly mentioned was their caring, loving, and “family member” style of interacting with them. Participants described their physicians by noting that they were “wonderful,” “sweet,” “loving,” “caring,” “gentle,” and “like a family member.” This communication style made the participants feel comfortable with their physicians, and participants stated that they were highly satisfied when their physicians interacted with them in this manner because it made them feel like they weren’t “just another number.” As Lourdes, a 32-year-old mother of four from Houston, said about one of her OB/GYNs, “She cared about me. It wasn’t just a job with her.”

Estrella, a 44-year-old mother of two from Houston, preferred her OB/GYN during her second pregnancy because she was “a very sweet lady”: “My second son’s doctor, she was so wonderful. She would hold my hand the whole time, and she was very loving and caring. She was very good, a very sweet lady.” Yessica, a 33-year-old mother of two from Houston, also noted that her doctor cared about her: “My doctor and my nurse, both of them, they gave me their time and let me know that they cared. They

were so kind, and they made me feel really comfortable.” In addition to being caring, Maura, a 32-year-old mother of one from Houston, described one of her physicians as delicate: “My doctor had the sweetest, most delicate attitude toward everything. She was so understanding. I really, really liked her. I loved her, actually. She was such a sweet lady! Her presence was very welcoming.”

The terms “gentle” and “nurturing” became synonymous with “caring” and “sweet” for certain participants from San Diego. Judith, a 44-year-old mother of three from San Diego, described her doctor during her second pregnancy as “gentle”: “My doctor with my second pregnancy, he was very caring and gentle. He was very concerned about the development of my child, so he would always take the time to explain things to me. He was gentle, so gentle. I felt very comfortable around him.” Esperanza, a 36-year-old mother of three from San Diego, saw an acupuncturist in conjunction with her OB/GYN and her midwife, and most of her interview focused on her relationships with her acupuncturist and her midwife:

With my acupuncturist, I had a very different dynamic than I think a lot of people do with their doctors. There’s intimate relationships that you hold with your healthcare providers, especially for long-term, and there was a different layer there. She was very caring, very nurturing, very gentle. There was definitely more of an intimate relationship with her. There was more trust. I really trusted her and knew she would have my best interests. My midwife was also very caring and gentle. She was caring, thorough, and more relaxed. If I had to sum her up in one word, it would be caring.

Flor, a 31-year-old mother of three from San Diego, described her OB/GYN during her third pregnancy as her favorite because “she really cared about [her]”: My third doctor was by far my favorite! We established a solid relationship with each other. We would joke and laugh—she really cared about me.”

As participants described how they favored their physicians’ caring and gentle communicative styles (which are traits associated with *personalismo*), a few participants explicitly noted that their favorite physician treated them like family members. Dulce, a 34-year-old mother of two from Houston, spoke about her midwife as if “she was another cousin or something!”:

My midwives were just so passionate about what they do! They would always ask me, “So, how are you doing? And how is your family doing? And how is your family life?” You know, they take so much time out to find out how you’re doing. You know that when you’re pregnant, you’re hormonal! They would even speak to my husband! I really liked that. It was like she was another cousin or something! That’s my favorite kind of doctor.

Beatriz, a 33-year-old mother of two from San Diego, also spoke very highly of her midwife with her second pregnancy:

My second midwife really remembered me. She seemed like she *really* remembered me, like, “Oh, hi! How are you? How’s everything? How’s your family?” She gave me her attention and her time. Talking to her was like talking to family. She was just so caring. It’s those things you want when you’re pregnant, that you just want to feel cared for.

Juanita, a 32-year-old mother of one from San Diego, echoed Dulce and Beatriz's sentiments when she stated, "Even though I saw different doctors at the clinic, I had my favorite doctor. She seemed like a family member. She really connected with me." Finally, Flor, a 31-year-old mother of three from San Diego, said, "Talking to [my doctor] was like talking to a family members. She would joke with me and she knew me, so it was much more personal and comfortable. We were very comfortable together."

Thus, as participants recalled their relationships with their physicians, one of the most frequently recurring comments was that they preferred their physicians who spoke to them in caring and supportive ways. Physicians communicated their support and their care for the participants by asking how their family members were doing, by joking with the participants, by paying attention to them, and by comforting them. Intertwined with this *personalismo* communication style was fact that they physicians took time to explain health-related information to the participants, which is the subject of the next code.

#### **"We Had a Very Open Line of Communication": Information-giving & Listening**

As participants discussed their preferences for the *personalismo* communication style and how they preferred physicians who talked to them as if they were family members, participants mentioned in the same breath that they appreciated that their physicians would take extra time to explain prenatal information to them. As Lara, a 32-year-old mother of two from San Diego, noted about her physician, "It *all* had to do with the open lines of communication that we had." Participants preferred physicians who made them feel valuable, and this was conveyed to participants when their physicians

took the time to listen to them, answered their questions thoroughly, and addressed their concerns.

Yessica, a 33-year-old mother of two from Houston, contrasted her favorite physician with her least favorite physician, noting that her favorite physician “paid attention to [her]”:

With my other doctor, she wasn’t in a rush to get out of the room, and she always asked me if I had questions for her. I would ask her about testing, breastfeeding, seizures, and anything and everything else I could think of. She would always answer my questions and talk through my medications with me. That’s what I loved about her. She was real open to me asking her questions, she had time for me, and she always wanted to research things for me. I really liked her.

Nayara, a 32-year-old mother of four from Houston, also contrasted her physicians as she described why her fourth physician was her favorite. She chose another doctor for her fourth pregnancy because she was unhappy with her doctor that she was seeing during her third pregnancy. When I asked her why her fourth doctor was her favorite, she responded, “I LOVED her because she listened to me! I would talk to her about my gestational diabetes fears and my health, and she really listened to everything I had to say. I appreciated that.” Last, Lara, a 32-year-old mother of two from San Diego, contrasted her civilian healthcare provider with her military healthcare provider and preferred her civilian OB/GYN because of her “open line of communication”:

With my first doctor, I think everything had to do with the open line of communication that we had. She explained everything a lot further with my son

than my military doctor did with my daughter. I was able to ask her more questions and actually spend time with her. She was such a sweet lady. She was an awesome, awesome doctor. She would tell me, “You’re doing great, this is where you are, here’s what prenatal testing is and does”—all of this stuff and information that you want and need to know as a mom! She always took her time with me, and that’s something I didn’t get with my military care.

Other participants echoed the open line of communication that Lara speaks of as they discussed how and why they appreciated when their physicians listened to them and “didn’t rush to leave” or “pay more attention to their other patients.”

Maria, a 40-year-old mother of two from San Diego, noted that she had a connection with her doctor because of his helpful, informative communication style:

My doctor was very helpful and very good. He would always sit down and talk to me, and he was always running late because he would actually sit down with me and wait for my questions. He would explain everything and say, “Do you have anymore questions?” and “Do you understand everything we talked about today?” He helped me so much. To have that connection is wonderful. I’m a person, not a number.

Evelia, a 32-year-old mother of two from San Diego, stated, “I really liked my doctors. They were really good at listening to me and explaining things. They always answered my questions on top of everything else they had to do. I felt important with them.”

Similarly, when Maura, a 32-year-old mother of one from Houston, recalled what she liked most about her one of her physicians, she stated, “One of my doctors really took



the time to explain things to me. If I had questions, she didn't brush me off. I really appreciated that. It made me feel important." She elaborated by noting, "She would always say, 'Any questions you have whatsoever, you call me!' A few times when I freaked out, I called her and left a message and she called right back! She told me what was going on, answered my questions, and took the time to explain to me what was going on and stuff like that. She was so awesome." Beatriz, a 33-year-old mother of two from San Diego, utilized the phrase "she didn't brush me off" to describe why she appreciated her physician: "She gave me her attention and gave me her time. If I had questions, which I always did, she was there for me. She was never in a rush to get me out of there. I felt like I was in good hands with her. She knew what she was doing and how to explain things." Finally, Juanita, a 32-year-old mother of one from San Diego, said she was thankful that her doctor did not rush their visits:

My doctor didn't try to get me in and out the door. At the clinic, they have limited time with you, and that's always my concern, like, "Oh, man, they only have ten minutes with me, that's it. If I'm not prepared with my questions already, that's it. I'll have to wait until my next appointment." With my favorite doctor, she was always persistent, telling me, "Let me know if you have any questions. Let me know if you have any concerns." She would always take her time with me and explain things to me. I always came out leaving happy every time I saw her. She always brought me to a good mood. She made time for me.

Thus, a majority of the participants were satisfied with their physicians' communication overall, particularly with one specific style and via one specific function: when their

physicians communicated with *personalismo* and when they spent time listening to the participants and answering their questions, respectively. This style and function, however, were mediated by the amount of time that the physicians had and were willing to spend with their patients. As participants described their favorite aspects of their physicians' communication, they consistently mentioned that their physicians made *time* for them: they took the time to listen, they took the time to ensure the participants were comfortable, they took the time to get to know them, and they took the time to explain information to them adequately. However, just as participants had physicians with whom they were satisfied, they had their fair share of dissatisfying physicians as well.

### **Unsatisfactory Relationships with Healthcare Providers**

When participants recalled their relationships with their favorite physicians, they often contrasted those relationships with their other physicians whom they disliked for a variety of reasons. Oftentimes, participants went through their first and/or second pregnancies with these physicians and then switched to other physicians because of dissatisfaction, change in employment/insurance, or change in location. The three main reasons that participants disliked these physicians were because they perceived them to be rough, impersonal, and overall poor communicators.

#### **“She Was Rough, Very Rough”: The Rough Physician**

The first reason participants disliked some of their physicians is because of their “rough” and “cold” communicative natures. Participants described these physicians as “dynamite doctors” who “lacked bedside manner” and ultimately “used a tough love kind of style.”

Eva, a 31-year-old mother of two from San Diego, noted that both her physician *and* the staff were rude: “With my second doctor, I couldn’t connect with anyone in there, not even the receptionist! Everyone was rude—the doctor was rude, the nurses were rude, the receptionist was rude. I thought to myself, ‘I need to get out of here. There’s no way I’m sticking with these people.’ So I didn’t. I switched.” In addition to being rude, Beatriz, a 33-year-old mother of two from San Diego, described her midwife as mean: “My first midwife was just straight up mean! Every time I would go see her, I felt like I did something wrong. She was just really mean about things. I saw her probably 3 or 4 times and I was like, ‘That’s it, I’m not seeing this lady anymore.’” Maura, a 32-year-old mother of one from Houston, anxiously recalled her relationship with one of her first physicians and said she would not visit her again because of her “roughness”: “She had no bedside manner! None! I couldn’t stand it! I was with her for a couple of years, but I just couldn’t take it anymore. When I had my first miscarriage before my son, she was SO not sympathetic. It’s so sad. She makes me NOT want to go to the doctor.” Eva, Beatriz, and Maura were able to switch physicians during their pregnancies, but the following participants could not switch mid-pregnancy and had to endure their physicians’ rough communication through the birth of their children (and sometimes after).

Estrella, a 44-year-old mother of two from Houston, was diagnosed with gestational diabetes during both of her pregnancies. She first mentioned that she preferred her physician who was kind and gentle, noting that her other physician was a “dynamite doctor”:

Because I was full-blown diabetic, I had the regular OB and the high-risk doctor. She monitored the weight and length of [my son] and how he was growing, and since I'm diabetic, diabetic babies grow faster. It was very stressful to see two doctors, and my high-risk was a dynamite doctor. She would just explode on me if my baby was a certain weight at a certain week. She was just awful! She would say, "Do you want your baby to die? Do you know that he's growing too fast? This baby is going to die." She was just awful and scared me a lot. I guess she was preparing me, but it didn't matter. She was tough, aggressive, and bold. I didn't like that about her at all.

Mireia, a 44-year-old mother of two from Houston, also disliked one of her physicians for the same reason that Estrella mentioned: "One of my doctors was just so hard. She was so rough. She expected me to do a lot of things that I should've been doing but wasn't. She'd get really upset if I wasn't losing weight when I should've been, but it was hard! She was rough, really rough. Yelling at me didn't really inspire me to do what she said." Yesenia, a 33-year-old mother of two from Houston, described her relationship with her second OB/GYN as a "never-ending horror story":

My doctor was rough, very rough. Whether it was about prenatal testing or my weight, she was just downright mean! She would tell me, "You're gaining too much weight. You're doing this wrong. You're doing that wrong." Right off the bat, I was problematic. I had a lot of issues with her, but I figured, you know what? I was just going to stick it out with her because my other doctor was an additional 30 minutes away and she was at the hospital where I was going to give

birth. I would tell myself, “It’s only 9 months. It’s only 9 months.” She was just so blunt. Then when it dealt with how my blood screening came back positive? Ugh, forget it. She was rough about that, too!

Finally, in perhaps the most extreme example of rough communication, Judith, a 44-year-old mother of three from San Diego, recalled her relationships with her physicians during her first pregnancy. She spoke of the stereotyping that occurred, as well as her physicians’ mean natures:

I was getting my healthcare at a clinic at a university, and I was on welfare. It was 1998, and the media said that it’s time to put people on public assistance in their place. We were poor and economically deprived, and I accidentally got pregnant. I didn’t feel well, so I asked if I could get a letter for my employer saying that I should take it easy. One of my doctors said, “Well, I worked until my 9<sup>th</sup> month of pregnancy. Why can’t you?” I didn’t get the best care from them. I kept feeling like they were treating me as if they were doing me a favor. I felt so terrible. They were so rude and cold. I felt like I was a second-class citizen, not a mother or a patient. I really felt the classification taking place. It really affected me and impacted my pregnancy negatively.

Thus, for this segment of the participants, at least one of their physicians during their pregnancies interacted with them in rough, cold, and rude manners. This manner of communication resulted in the participants’ feeling stressed, anxious, and dissatisfied with their care. A few participants even went as far as to say that their physicians’

communication “wrecked” their pregnancy experience, which ultimately left them highly dissatisfied with their physicians and their care.

### **“I Was Just Another Number”: The Impersonal Physician**

In addition to dealing with physicians who were rough and rude, participants had physicians who they perceived were impersonal. As I mentioned in the previous section of this chapter, participants preferred physicians who communicated in ways that are characteristic of *personalismo*; when their physicians were impersonal, participants noted that they felt unimportant and dissatisfied with their care.

Dulce, a 34-year-old mother of two from Houston, had both midwives and OB/GYNs during her two pregnancies. When she contrasted her midwives’ care with her physicians’ care she noted that doctors are “just so clinical”: “That’s just the way it is. They’re like procedure, procedure, procedure. The doctors are just typical doctors. They never took the time to find out how I was doing or to talk to me and get to know me.” Other participants also spoke of their physicians’ “clinical nature” by describing them as disconnected, non-personalized, and “not there.” Juanita, a 32-year-old mother of one from San Diego, noted that her one of the physicians who would see her routinely at the clinic did not seem interested with her health and how she was doing: “Yeah, my doctor was there, but he wasn’t *really* there. He would just go through the routine with me. I don’t even think he knew my name! He didn’t seem like he cared at all.” Paula, a 33-year-old mother of three from Houston, said her doctor did not make her feel important:

With my doctor, I felt like I was just any other patient. I didn’t feel like I really connected with her. I felt like she was so disconnected from everything. I didn’t

feel like she really understood me. I just kept her because I already had her with my first pregnancy and didn't feel like starting a new relationship all over again. She was just so... average. She didn't make an effort to make me feel comfortable or show me that she really cared about me as a person.

Dora, a 32-year-old mother of one from Houston, extended Paula's sentiments by noting that one of her physicians made her pregnancy "horrible":

I just felt that with my doctor, I was sad because it's supposed to be a good time in my life, and instead of making it better for me, she was just going through the routine of it. Instead of being happy for me, she was like, "Okay, you're just another patient, just another number." I didn't care for her at all. She didn't show me that she actually cared about me and my baby. I felt like it was the opposite. She was horrible. She never took a personalized approach to me.

Thus, this small segment of the participants had a physician who communicated with them in impersonal and disconnected manners. Participants reported that these physicians made no effort to get to know them personally, nor did they convey to their patients that they truly cared about them and their well-being. Although it seems as if having physicians who communicate roughly and impersonally lie on the less positive end of the patient-centered communication spectrum, a majority of the participants noted that they had at least one physician who did not allow for open communication at all. This communicative shutdown, participants noted, was worse than being treated in a rough or impersonal manner. Participants noted that they preferred having physicians

who would take the time to communicate with them and explain important aspects of their pregnancies to them.

### **“My Doctor Was An In-and-out Doctor”: Lack of Communication and Explanation**

Although participants had physicians who communicated with them in rough and impersonal manners, they were *most* disappointed with physicians who did not provide a space for them to communicate at all. Participants described how some of their physicians would not talk to them or explain procedures, and ultimately they “had to beg” information out of them. This resulted in high levels of uncertainty regarding a multitude of issues associated with their prenatal care, including prenatal sickness, blood pressure, and prenatal testing.

One of the participants’ most frequently mentioned phrases during this segment of interviews was “in and out”. The “in and out physician,” according to their experiences, is a physician who has too many patients, too much stress, and too little time. Flor, a 31-year-old mother of three from San Diego, visited both low-income clinics and insurance-covered private practices during her three pregnancies. Much of her narrative compared and contrasted the care she received at both types of facilities and focused on the less-than-optimal care she received at the low-income clinic: “The doctors I had at the clinic were just ridiculous—in and out, in and out, a different doctor each time I went—I felt like I could never get a word in with them. Not only that, but I felt like they didn’t want to hear what I had to say, either.” Nayara, a 33-year-old mother of four from Houston, also described one of her physicians as an “in and out, in and out” kind of doctor: “I didn’t like my second OB/GYN because there was no open



conversation! She wouldn't actually talk to me or tell me what was going on. It was just in and out, in and out. Even when I would try to talk to her about prenatal testing, nothing—in and out, in and out.” Marita, a 34-year-old mother of three from San Diego, grimaced when she detailed her relationship with her physician she saw during her second pregnancy because of her dissatisfaction with her care:

My second doctor was so in and out, in and out. She was like, “Okay, I have things to do. I have things to do.” So, it’s kind of like the saying they have when you go to the doctor—she was just in and out. I would tell her and explain to her what I wanted and needed and what was going on and she would immediately cut me off and say, “No, this and this.” I couldn’t get a word in when we would meet because just as soon as she was in the room, she was out the door.

Mireia, a 44-year-old mother of two from Houston, also noted that her physician was an “in and out” doctor: “With one of my other doctors, it was so typical—short, minimal, he always had better things to do, and communication was only what you would beg of him. If I wanted to know something about anything, I had to try to keep him in the room for longer than five minutes! In and out, he never said or explained anything.” Dora, a 32-year-old mother of one from Houston, said her “get you in, get you out” doctor always seemed as if she was on a time crunch:

With one of my doctors, I felt like every time I would go there, it was a “get you in, get you out” type thing. I would think to myself, “Oh, that’s it? Good thing I didn’t have any questions.” They didn’t talk to me about anything there... although, come to think of it, I would always have questions because they would

never take the time to explain anything to me! I felt like all the time I was on a time crunch with her, and she would “talk” to me, but she didn’t really care about me, you know what I mean? I hated going to see her. It was like I was a number to her. She didn’t really care about me.

Yessica, a 33-year-old mother of two from Houston, described her doctor as someone who “had too much to do”: “One of the doctors looked like she just had too much on her plate. She never offered any research to me and never gave me any information. I felt like I was just kind of wandering around with her.”

Thus, just as participants had physicians who made them feel comfortable and treated them like family members, they also had physicians who were rough, impersonal, and non-communicative. Participants recalled that some of their physicians were the “in and out” type of physician, meaning they did not “go above and beyond” to explain prenatal health issues to the participants or make them feel important. This mode of communicating and interacting with the participants made them feel unimportant and dissatisfied with their physicians and with the care they received.

### **Discussion: Mexican-American Women, Prenatal Decision-Making, Relationships with Providers, and Patient (Dis)satisfaction**

This chapter has sought to explore Mexican-American women’s relationships with their healthcare providers during their pregnancies, particularly as it relates to the role of their physician in the participants’ refusal of the amniocentesis. Broadly, research has found that shared decision making about genetic testing is often complicated, due to the ethical and moral issues associated with the outcomes of the test (Bylund & Imes,

2005); that women are often not aware of screening implications and were passively involved in decision-making with their physicians (Seror & Ville, 2009); that physicians need to be cognizant of the roles family members play in the decision-making process (Downing, 2005); and that women oftentimes view their physicians as not just doctors, but also as moral authority, advocates for particular treatments, and supporters of women's choice (Downing, 2005).

More specifically, research that explores Mexican-American women's engagement with their physicians during prenatal testing has found that Mexican-American women prefer their physicians to be more direct with them when discussing whether or not they should undergo the amniocentesis (i.e., discuss with the participant what the physician thinks is best for them) (Browner, Preloran, & Cox, 1999); that Mexican-American women's physicians often use the "mutuality" approach, meaning that they share decision-making responsibility with the patient (Browner, Preloran, Casado, Bass, & Walker, 2003); and that physicians deployed medical jargon during their consultations with Mexican-American women (Browner et al., 2003). Despite these findings, however, there is scant literature on second- and third-generation Mexican-American women's experiences with amniocentesis decision-making and their healthcare providers, as well as their patient-provider communication preferences. How did the participants engage in decision-making about the amniocentesis procedure with their physicians? What was the role of their physicians? Were participants satisfied with the care they received during their pregnancies, and how did their physicians

communicate? What sorts of factors enabled and constrained patient-provider communication about the amniocentesis procedure?

Overall, most participants engaged in shared decision-making with their physicians when discussing the amniocentesis procedure, and for the most part they were reportedly very satisfied with their physicians at this pivotal moment during their pregnancies. Almost all 30 participants had at least one physician during their pregnancy who explained the amniocentesis procedure to them, along with its risk and benefits, and who engaged in a dialogue with them about whether they wanted to undergo the procedure. Both parties (the patient and the physician) participated in the process, and participants noted that their physicians created a trusting communicative environment where they felt comfortable enough to express their wishes to reject the amniocentesis. This is important because research has found that Mexican-American women will sometimes accept the amniocentesis, even if they truly do not want the test, because they feel that their physician wants them to go through with the procedure and they do not want to disappoint their physician (Browner & Preloran, 2004). With this group of participants, however, that did not occur. 29 out of 30 participants did not want the amniocentesis and did not hesitate to tell their physicians that they did not want the test. Participants mentioned that most of their physicians accepted and supported their request, and that they were overall fairly satisfied with this moment during their prenatal care.

This moment of shared decision-making is what I am referring to as reciprocal communication, which is a concept similar to Browner and colleague's concept

“mutuality” (Browner et al., 2003). I refer to this shared decision-making moment as reciprocal communication because participants described that moment with their physicians as a reciprocal exchange, i.e. “I did not want the test. The doctor brought up the test and explained it. I told him I didn’t want it. He said that was fine.” Most participants described this as an easy-going, low stress encounter that was akin to other decisions they had to make during their pregnancy. Some participants did not have supportive physicians throughout their pregnancies, though, and described their physicians as being “amniocentesis happy.” These physicians, according to participants, would not take the patient’s “no” for an answer and repeatedly recommended that they undergo the exam. Although only 7 participants out of 30 had a physician who communicated in this manner, the encounters were so traumatic that participants had to get their extended family members involved in their defense, fight back with the doctors, and ultimately switch physicians.

This points to a key question about the relationship during the patient and the healthcare provider during her pregnancy—what is the role of the physician when it comes to the amniocentesis procedure? Ultimately, physicians, just as genetic counselors, should strive to be non-directive when discussing the amniocentesis procedure with the patient. In other words, genetic counselors and other physicians should be “value neutral” and solely provide information about the test to the patient, allowing her and her family to make the best decision for them. It is understood that physicians will have their own values and beliefs related to the test, yet they offer their thoughts about the risks and benefits and not influence the patient toward one option or

the other. However, as Rayna Rapp (2000) and other scholars have shown, healthcare providers often have their own implicit and explicit biases about this procedure, disability rights, and what it means to have a child with a disability, and these biases and values often seep into the communicative encounter. Certain scholars have taken it a step further by arguing that physicians *should* be directive counselors when discussing the amniocentesis procedure and should persuade participants to reconsider their decisions. Yarborough, Scott, and Dixon (1989), for example, argue that in certain cases physicians should persuade participants to reconsider their decisions because they should insure that participants “act with full knowledge of the moral consequences of their decisions” (p. 139). But when does directive counseling become *too much* counseling? Participants noted that they became very frustrated, irritated, and angry when their physicians repeatedly told them to reconsider their initial rejection of the amniocentesis. Some physicians even brought out visual aids such as gene charts to further persuade the participants to reconsider. I do not know what sorts of medical principles were guiding the physicians actions in these encounters (directive/non-directive counseling), nor do I know what the physicians’ intentions were in persuading the participants to reconsider their decision (patients’ well being, opinions about birthing children with a genetic issues, consideration of the participants’ futures, etc.). I can be certain of one notion, however—participants were very dissatisfied when their physicians repeatedly attempted to persuade them, and they noted that they wished their physicians would have accepted their initial rejection of the test. Thus, this segment of the participants preferred the non-

directive style of counseling and were more satisfied and comfortable when their physicians communicated with them in this manner.

The second theme that emerged during the interviews was the participants' satisfactory relationships with their healthcare providers. Although I initially asked participants about their relationships with physicians during the amniocentesis procedure, participants wanted to share their stories about their physicians throughout the duration of all of their pregnancies. For the most part, participants were satisfied with their physicians overall and pointed to two key aspects of their physicians' communication that they valued the most: the physicians' successful performance of *personalismo*, and the physicians' outstanding information-exchange abilities. Even though I did not explicitly ask about whether physicians exhibited *personalismo* traits or whether they were good at explaining health-related information, these two concepts surfaced in almost each interview. Participants consistently mentioned that their physicians communicated with them in loving, caring, and gentle ways; moreover, they were satisfied with this communication style because it made them feel comfortable and, more importantly, valued as a patient.

These communicative traits are representative of *personalismo*, a long-supported healthcare concept which is an cultural extension of the importance of one's relationships. *Personalismo*, according to Caballero (2011), is "the expectation that a Hispanic/Latino individual will develop a personal relationship with their healthcare provider" (p. S12). This emphasizes a relationship between the patient and physician where the physician is genuinely interested in the patient's life and acts as both a

physician *and* a friend (Andrews & Herberg, 1999; Caballero, 2011). In this case, participants were satisfied when their physicians acted as a friend or family member and preferred this communicative style. This theme supports recent research conducted by Bergman and Connaughton (2013), which found that during their prenatal care, Hispanic women preferred a friendly relationship with physicians, effective medical care, and understanding of information. What cannot be ignored, however, is how these traits—loving, caring, gentle, warm, and supportive—are also gendered means of communicating. In this case, participants not only preferred a physician who genuinely cared about them, but they also preferred a physician who communicated in traditionally feminine styles.

In addition to the *personalismo* component, participants also reported that their physicians excelled at the information exchange component of their relationships and their doctor visits. They appreciated that their physicians would make time to truly listen to their questions and exchange information with them, and they perceived that this quality strengthened their relationships and made them more satisfied. Patient-centered care, as discussed by Epstein and Street (2011), has many dimensions, including information exchange, managing uncertainty, and establishing trust and rapport, among others. If done well, patient-centered care can lead to patient satisfaction and better health outcomes, and the main component within the amniocentesis context that contributed to higher patient satisfaction for this group of participants was effective information exchange. Effective information exchange within this context was more than just a conversation about prenatal testing information; rather, it was a set of



conversations in which the physician created a comfortable communicative environment, elicited the participants' questions, tailored the amniocentesis information to that specific information, and minimized any uncertainty the patient had about the process. This led to higher satisfaction for the participants and better relationships with their physicians overall.

As I mentioned earlier, however, these communicative exchanges were mediated by one important factor: time. Participants consistently prefaced their information exchange encounters by noting that their physicians "took the time" to listen to them and "took the time" to answer their questions and make them feel important. Time is an important component of the patient-provider relationship that can lead to more patient satisfaction (Dugdale, Epstein, & Pantilat, 1999; Robbins, Bertakis, Helms, Azari, Callahan, & Creten, 1993). Perhaps, though, what is most important is not the actual amount of time the physician has with the patient, but rather the communicative strategies the physician uses during his or her time with the patient to enhance the care and patient-physician relationship with the time available. Dugdale and colleagues (1999) argue that physicians can practice patient-centered communication during healthcare encounters and maximize the time they have with patients by utilizing the following strategies: setting an agenda early in the visit, listening actively to the patient's story, paying attention to the patient's emotional agenda, soliciting the patient's opinions, and taking advantage of the patient's personal knowledge. It is unknown objectively whether the participants' physicians had more time to interact with patients, thus enhancing their relationship and satisfaction, or whether they had minimal time and

better communication skills. Regardless of the physicians' time frames, participants perceived that their physicians made time to engage in conversations with them and get to know them more deeply, which contributed to higher patient-provider satisfaction and reduced uncertainty during their pregnancy.

The third and final theme that emerged from conversations with participants was their unsatisfactory relationships with some of their healthcare providers. Although a multitude of issues could have contributed to this dissatisfaction (provider bias and cultural clashing, to name a few), the three main reasons that participants were unhappy with certain physicians were because they were rough, impersonal, and because they would not take the time to communicate with the participants. Over the course of their multiple pregnancies, about half of the participants had at least one physician who communicated in one of the aforementioned manners. Just as participants preferred when their physicians communicated in gentle and caring ways via reassurance, support, and informal conversations, participants were dissatisfied when their physicians “lacked bedside manner” and “did not take the time to get to know” the participants. Again, one of the key relating variables that surfaced during participant interviews was the notion of time. Participants consistently rationalized that their physicians' rough and impersonal communicative styles were caused by lack of time. Some of the participants consistently noted that their physicians did not have the time to be gentle and did not have the time to get to know them because of too many patients or not enough time to spend during the encounter with each individual patient. Their perception that the doctor did not have enough time to spend with them and get to know them contributed to dissatisfaction with

their healthcare providers, with their care, and with an overall feeling that their physicians did not take a personalized approach to their prenatal care.

Thus, this chapter has sought to explore the role of the participants' physicians in their amniocentesis decision-making, as well as their perceptions of their care and of their relationships with their physicians. One of the most positive findings of this chapter is that a majority of the participants engaged in shared decision-making with their physicians when discussing the amniocentesis procedure, and this decision-making was facilitated by the physicians' caring and gentle communicative styles, as well as their ability to engage in thorough and effective information exchange with the patients. On the other hand, participants also had their fair share of physicians with whom they were dissatisfied, and this dissatisfaction was caused by physicians who communicated in rough and impersonal manners. The key variable that mediated participants' satisfaction was time—participants were more satisfied with their physician and with their care overall when they perceived that their physician “took the time” to get to know them personally; conversely, when participants perceived their physicians “weren’t taking any time” to get to know them or utilize a “personalized approach” to their care, they were more dissatisfied with their physicians and with their healthcare overall. In the next chapter, I will discuss the relationships between and among religion, ethnicity, family, and physicians as they shaped Mexican-American women’s (dis)engagement with the amniocentesis procedure and conclude with suggestions for clinicians, limitations, and future directions.

## CHAPTER VII

### CONCLUSIONS

Consumers (or, in this case, nonconsumers) of a biomedical technology can be seen as experts capable of analyzing its burdens and benefits and casting a rather different light on contests for meaning and rationality.

~ Rayna Rapp (1998), p. 48

The amniocentesis procedure—one of the most routinized prenatal diagnostic tests—has both benefits and burdens associated with the technologies utilized during the procedure and also the types of information it can provide to pregnant women. A highly contentious topic for feminist reproductive rights scholars and activists, it is widely agreed upon that discourses about prenatal testing generally reflect either of two different models: in public health discourses prenatal testing can help alleviate the frequency of children being born with various birth defects, whereas in “reproductive autonomy” discourses prenatal tests can provide pregnant women with valuable information that can both expand their reproductive choices and help them plan for their future (Lippman, 1991, p. 22). Another view that can be added to these conceptualizations is the notion of informational burden, a term I have coined to describe what Lippman (1991) and this study’s participants describe as the “internal tension revealed in the coexistence of quite contradictory constructions of testing that may be equally valid,” meaning a test that could potentially give women *some* amount of control over their pregnancies, yet it also presents the burdensome decision of what to do with diagnostic information that one was not expecting or does not want. With this dissertation, I set out to explore the ways in which the amniocentesis procedure is

socially constructed for Mexican-American women in San Diego and Houston, as well how the participants viewed their ethnic identities as contributing to this sense-making process and the roles of women's family members and healthcare providers in the decision-making process. I found that out of 30 participants, 29 refused to undergo the amniocentesis procedure because it would not change the outcome of their pregnancies and because the amniocentesis procedure would present them with more stress and information that they did not want or need. Moreover, family members contributed to this process by supporting participants as they made their decision and also by sharing *their own* perceptions of and experiences with the amniocentesis, and these family narratives evolved into very important health information sources that the participants utilized to make their decision. Finally, for the most part, participants engaged in informed decision-making and shared decision-making with their physicians as they evaluated whether to undergo the amniocentesis procedure, and participants noted that they preferred physicians whose communication styles were characteristic of the *personalismo* style and who took the time to explain health-related information to them.

Overall, this dissertation makes several important contributions to literature that explores Mexican-American women's experiences with amniocentesis decision-making. First, I sought to explore the ways in which the participants perceived and performed their ethnic identities because, at a broader level, women's healthcare experiences are undoubtedly situated within a complex web of ethnic, cultural, gendered, and familial factors. Moreover, despite good intentions on behalf of culturally competent healthcare communication models, Mexican-American women are often essentialized and

stereotyped during medical encounters (Hunt & de Voogd, 2005) when physicians invoke “clinical myths about the cultural other” that guide their practice and their communication skills.

As participants discussed their perceptions of their ethnic identity, it became evident that participants perceived and performed their ethnicity in a myriad of ways. In addition to identifying with a multitude of terms used to signify Mexican descentance (Houston participants as overwhelmingly Hispanic and San Diego participants as overwhelmingly Chicana or Mexican), participants also spoke Spanish to varying degrees and practiced their religions and spiritualities to varying degrees. Although some physicians might think that Latina patients prefer to speak Spanish during the medical encounter or will refuse prenatal testing for strictly religious reasons (Hunt & de Voogd, 2005), these findings were not supported in this study. Rather, the themes that emerged throughout conversations with participants provide new ways to conceptualize what it means to be a Mexican-American female patient and provide support for past research that suggests that religion and spirituality are fluid and negotiable identity components. The chapter on Mexican-American ethnic identities is not meant to provide another essentializing typology of “Mexican-American female patients,” but rather is meant to provide a starting point for future explorations of the multiplicities of Mexican-American ethnic identities and how these identities contribute to, shape, and relate to health-related decision-making and health outcomes.

Second, I sought to explore the ways in which Mexican-American women perceived the amniocentesis procedure, the ways in which they interacted with it, and

how family members contributed to this process. Although past research suggests that Mexican-American women generally accept the amniocentesis procedure at rates comparable to those of Caucasian women and women of other races/ethnicities (Browner, Preloran, & Cox, 1999; Markens, Browner, & Preloran, 2003), this also was not supported in my study, considering that 29 out of 30 participants in this study refused to undergo the amniocentesis. Participants listed a variety of reasons for rejecting the amniocentesis procedure, such as they did not want the test because of perceived risks; they knew they would not undergo an abortion, so the test information was unnecessary; and knowing whether their child had a disorder would not change their intention to keep their pregnancy to term.

The most important findings from this section are fivefold: (1) participants constructed their own interpretations of the amniocentesis procedure based upon a “homegrown understanding” of the procedure, which was shaped by personal interpretations of risk and family members’ fear narratives; (2) from a health information seeking perspective, participants’ family members emerged as the most important and influential source of health information (as opposed to books or websites), and family members’ stories were powerful sources of influence as participants weighed the advantages and disadvantages of the amniocentesis; (3) participants constructed various definitions of “healthy babies,” which varied significantly from certain biomedical constructions; (4) amniocentesis test information was perceived as a stressful burden that would have no bearing on the pregnancy outcome, as opposed to information that could help them plan their future; and (5) there was a disconnect between participants’

interpretations of how the blood screenings and amniocentesis procedure operate and what they test for versus medical definitions and understandings of how the diagnostic tests operate and the kinds of information the tests can provide. With this homegrown knowledge of the amniocentesis procedure, what it tests for, and what its false positive rates are, the participants operated from experiential knowledge bases as they evaluated the amniocentesis procedure and rejected it.

The participants' homegrown knowledge and their deployment of their homegrown knowledge during their decision-making processes, I argue, are evident of their agency during their medical decision-making. At the outset of this project, I naively assumed that at least half of the participants would want to undergo the amniocentesis procedure because of the benefits and the reassurance that the test information could provide. I quickly realized throughout the first five interviews or so that I was wrong because the participants perceived the amniocentesis procedure in radically different ways. Participants spoke of their pregnancy as containing their babies, babies that would be wanted and loved regardless of whether they had a genetic or chromosomal disability. Moreover, participants spoke of this decision as *their* decision and *their* choice, a choice that they felt strongly about and one that would not falter. This is evidence of the participants taking their health decisions into their own hands and rejecting a test for which they saw no need or utility. Feminist reproductive scholars Silliman, Gerber Fried, Ross, and Gutierrez (2004) have noted that all too often, research that explores women of color's reproductive histories focuses too much on injustice and abuse and presents an impartial history. Dorothy Roberts (1997) argues that these impartial histories construct



women of color as passive puppets within the medical system and, together with Silliman and colleagues (2004), calls for research that showcases women of color's agency within the healthcare system, particularly as it relates to their reproductive activism and decision-making. This is but one example that showcases Mexican-American women's agency within their reproductive decision-making. Although some participants had physicians who pushed the amniocentesis procedure during their medical visits, participants spoke of how they "would not budge" and kept refusing the procedure. Just as a woman's right to choose to undergo the amniocentesis procedure should be supported, so, too, should a woman's right to refuse the amniocentesis procedure be supported as well. This is but one component of larger reproductive rights visions that call for better access to healthcare and more culturally competent physicians, to name a few (Silliman, Gerber Fried, Ross, and Gutierrez, 2004).

Third, I sought to explore the role of participants' physicians in their amniocentesis decision-making experiences and their preferences for patient-provider communication. Contrary to literature that describes how providers stereotype Latina patients (Hunt & de Voogd, 2005), I found no evidence of stereotyping; rather, participants described that, for the most part, they engaged in informed and shared decision-making with their physicians. Less than one-third of the participants had physicians who were pushy about the test, and a few participants reported that their physicians did not recommend the amniocentesis at all, perhaps because their blood screenings tested negative for genetic and chromosomal anomalies. Moreover, participants spoke of how certain physicians took extra time to explain information to

them, establish relationships with them, and communicate in a *personalismo* style. On the other end of the spectrum, participants described their physicians who communicated in cold and rough manners and did not take the time to establish a relationship with them, which contributed to higher levels of dissatisfaction with their care. One component that mediated participants' relationships with their physicians was time. Participants were more satisfied with their physicians when they perceived that they *took the time* to get to know them and explain information to them; conversely, participants were more dissatisfied with their physicians when they *did not take the time* to establish relationships with them and explain information to them.

### **Recommendations for Healthcare Providers**

Given the aforementioned research findings, I have three recommendations for healthcare providers and their communication with Mexican-American patients about prenatal diagnostic procedures. First, physicians should discuss the procedures with participants and spend a few extra moments (if possible) asking the participants to explain back to the physician what the blood screenings, ultrasounds, and amniocentesis procedure test for and the types of information they can provide. During interviews, participants inaccurately described the diagnostic procedures and what they test for, and these perceptions, couple with the risks associated with the procedures, were very important factors that persuaded the participants to reject the amniocentesis. Physicians should ensure that the participants have accurate knowledge bases to gauge whether they will accept or reject the amniocentesis because, as I have mentioned throughout this

dissertation, having accurate knowledge bases of a procedure is a hallmark of informed and shared decision making.

Second, during the medical encounter, physicians should explicitly ask patients about their existing knowledge of prenatal diagnostic procedures to uncover how their homegrown knowledge bases are shaped and influenced by family members. In this study, participants' family members were influential sources of health information, and their family members' experiences with the amniocentesis procedure (pain, risk, false positive rates, and amniotic fluid leakage) "scared them" out of undergoing the amniocentesis. Once physicians ask about the role of family members in the amniocentesis decision-making process, they can gauge the types of information participants have and offer medical information about the tests so that patients can have multiple knowledge bases to work with as they make their decision.

Third, physicians should be cognizant of the ways in which their communicative styles enhance or destroy women's pregnancy experiences. In this study, participants noted that physicians who spoke to them in caring, family-like ways enhanced their relationships and their pregnancy experiences. Participants looked forward to seeing their physicians and were happier during their pregnancy. On the other hand, participants whose physicians communicated in a rough manner and did not take time to explain health-related information noted that they hated going to the doctor and, in some instances, skipped appointments or switched physicians altogether. The participants' in this study preferred physicians who communicated in caring and empathetic ways, and

this communicative style might be particularly useful for certain Mexican-American women during their pregnancies.

### **Limitations & Future Directions**

This study has limitations that need to be addressed. First, given that this was a qualitative study, the findings cannot be generalized to the larger Mexican-American female patient population here in the U.S. The findings can, however, provide a starting point for general themes and patterns that can be complemented and explored with quantitative research studies. Further research could apply the themes from this study in a survey format to gather data that can be generalized. Second, I was not able to observe patient-provider interactions nor interview physicians about their perceptions of their communication skills or communicative interchanges. Future research should observe Mexican-American women's healthcare interactions with their physicians to understand and explore the ways in which decision-making ebbs and flows within the medical encounter and to explore how physicians and patients communicate about prenatal diagnostic tests' procedures and findings. Participants placed faith in the blood screenings and ultrasounds and reported that if those two procedures were negative, then they "knew they would be okay." As participants explained their reasoning, however, it became apparent that the participants did not have accurate knowledge of what the blood screenings and ultrasounds can tell them about their pregnancy. This points to the actual communication that occurs between patients and physicians about prenatal diagnostic procedures. Although I was not able to observe patient-provider communication about prenatal diagnostic procedures, future research should explore the communicative

interchanges between healthcare providers and patients about prenatal testing and ask the women after the interchange to explain their knowledge of what the procedures test for and how they operate. This could show the concordance and disconnect between clinicians' communication of prenatal testing and patients' understanding of that information and knowledge. Moreover, given that many of the participants perceived the conversation about the amniocentesis procedure as a "routine interaction" during their pregnancies, interviews with physicians would be particularly helpful to explore whether physicians perceive the amniocentesis as a routine procedure as well.

In conclusion, this dissertation set out to explore the social construction of the amniocentesis procedure for Mexican-American women from Houston and San Diego. As Rayna Rapp (1998) has noted, pregnant women are located at the intersection of gender relations, reproductive rights, disability rights, and genetic discourses and become "moral pioneers" when they decide who is worthy for "entry into the human community" (p. 68). By interviewing Mexican-American women about their perceptions of the amniocentesis procedure, I was able to gain a snapshot of the difference between "a scientific message of obligatory universality and the concrete, local contradictory particularities of applied technology as an aspect of a lived dilemma" (Rapp, 1998, p. 68). By rejecting the amniocentesis procedure, the participants were active agents in their reproductive decision-making processes and drew upon experiential knowledge bases to make sense of the amniocentesis, what it tests for, and why it was not a good option for them.

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APPENDIX A  
INTERVIEW GUIDE

<b>Name</b>	
<b>Identification</b>	
<b>Age</b>	
<b># of pregnancies</b>	
<b>Marital status</b>	
<b>Religion</b>	

**Experiences of Making Decisions about Prenatal Testing & Amniocentesis**

1. To get started, tell me about your pregnancy.
  - a. Was it planned/not planned?
  - b. How would you characterize your health during your pregnancy?
  - c. When you first found out about your pregnancy, how much did you know about prenatal testing?
    - i. (If not much) Did you start searching for information to help you understand it? How did you use this information?
    - ii. (If a lot) Can you explain to me what prenatal testing tests for?
  - d. When did the decision about whether or not to undergo prenatal testing come up (either just for you, with you and your partner, with you and family members)?
    - i. How did making this decision go? How did you feel? Who did you talk to about it?
    - ii. (If in a relationship) How did your partner contribute to making this decision?
    - iii. How did family members contribute to making this decision?
  - e. You said earlier that you are a \_\_\_\_\_ (or practice X religion).
    - i. What does this mean to you?

- ii. How did it contribute to your decision about whether or not to undergo prenatal testing?
- f. You said earlier that you identify as (2<sup>nd</sup>/3<sup>rd</sup> Mexican/Mexican-American/Hispanic/Latina).
  - i. What does this term mean to you? Do you identify with it strongly?
  - ii. How do you think it contributed to your decision about whether or not to undergo prenatal testing?
  - iii. How do you think your experiences might compare to those of your mother, aunts, and/or grandmothers?

### **Perceptions of Healthcare Professionals' Communication**

1. To get started, how many doctors did you see over the course of your pregnancy?
  - a. How did those interactions unfold? What were they like?
  - b. How would you characterize/describe your relationships with your healthcare providers during your pregnancy (physician/OB GYN/genetic counselor)?
  - c. Which was the best/closest and the worst? Can you give me an example?
2. Did your healthcare provider offer prenatal testing to you? What about an amniocentesis?
  - a. What was this conversation like?
  - b. What are your overall thoughts about your healthcare providers' communication when you were discussing prenatal testing with them?
  - c. Could you give me an example?
3. What kinds of information did they give you when you were discussing prenatal testing with them?
  - a. How did they communicate this information?
  - b. During and after this conversation, did you feel like you adequately understood what prenatal testing and amniocentesis entail?
4. When you were in the process of making a decision about prenatal testing, how did your physician contribute to this process?

### **Final Thoughts**

1. Is there anything else you would like to tell me about your experiences of deciding whether or not to undergo prenatal testing?

## APPENDIX B

### TABLE OF PARTICIPANT DEMOGRAPHICS

<b>Name</b>	<b>Age</b>	<b>Location</b>	<b>Marital status</b>	<b>Highest level of education</b>	<b># of pregnancies</b>	<b># of children</b>
Estrella	44	Houston	Married	Bachelor's degree	2	2
Isa	34	Houston	Married	Some college	5	4
Nayara	33	Houston	Married	Some college	4	4
Lourdes	32	Houston	Married	Some college	4	4
Mireia	44	Houston	Married	Some college	2	2
Noelia	37	Houston	Married	Bachelor's degree	2	2
Maura	32	Houston	Married	Some college	3	1
Dulce	34	Houston	Married	Some college	2	2
Paula	33	Houston	Married	Some college	2	3
Yessica	33	Houston	Married	Some college	2	2
Dora	32	Houston	Married	Some college	1	1
Ysabel	33	Houston	Married	Some college	2	2
Graciela	37	Houston	Married	Bachelor's degree	1	1
Yesenia	33	Houston	Married	Some college	2	2
Eva	31	San Diego	Single	Bachelor's degree, working on master's degree	2	2
Judith	44	San Diego	In a relationship	Master's degree	3	3

Lara	32	San Diego	Married	Bachelor's degree	2	2
Anita	32	San Diego	Married	Some college	1	1
Evelia	32	San Diego	In a relationship	Some college	2	2
Juanita	32	San Diego	In a relationship	Some college	1	1
Marita	34	San Diego	Married	Some college	3	3
Esperanza	36	San Diego	Married	Bachelor's degree	5	3
Beatriz	33	San Diego	Married	Some college	2	2
Melania	40	San Diego	Married	Bachelor's degree	2	2
Luciana	31	San Diego	Married	Some college	1	1
Flor	31	San Diego	Married	Some college	3	3
Marisa	34	San Diego	Married	Some college	2	2
Elena	39	San Diego	Married	Bachelor's degree	1	1
Juana	32	San Diego	Single	Some college	1	1

## APPENDIX C

### TABLE OF THEMES

Categories	Codes
<b>Ethnic Identity</b>	
Ethnic Identity	<ul style="list-style-type: none"> <li>• <i>“Hispanic—That’s What I Am”</i>: Houston Participants and the Hispanic Identity</li> <li>• <i>“I’ll Always Have My Mexican Roots”</i>: San Diego Participants and the Chicana/Mexican Identity</li> </ul>
Spanish-speaking (In)abilities	<ul style="list-style-type: none"> <li>• <i>“I Don’t Know Spanish. It Doesn’t Really Matter”</i>: Houston Participants and the Inability to Speak Spanish</li> <li>• <i>“Of Course I Speak Spanish. I Was Raised on It!”</i>: San Diego Participants and the Ability to Speak Spanish</li> </ul>
Religion & Spirituality	<ul style="list-style-type: none"> <li>• <i>“I’m a Diet Coke Catholic!”</i>: The Non-practicing Catholic</li> <li>• <i>“I’m a Baptist Now”</i>: The Non-Catholic</li> <li>• <i>“I Don’t Practice a Religion, but I’m Definitely Spiritual”</i>: Non-organized Spirituality</li> </ul>
Relational Gender Politics	<ul style="list-style-type: none"> <li>• <i>“My First Marriage Just Didn’t Work”</i>: First Marriage Woes &amp; Second Marriage Bliss</li> <li>• <i>“He’s My Biggest Support”</i>: First Marriage Support &amp; Partnership</li> </ul>
<b>Amniocentesis Refusal</b>	
The Amniocentesis: An Unnecessary Prenatal Test	<ul style="list-style-type: none"> <li>• <i>“It Just Wasn’t Necessary”</i>: No Reason for the Procedure</li> <li>• <i>“It Won’t Change the Outcome”</i>: Intention to Keep the Pregnancy</li> <li>• <i>“What Would I Do with the Information?”</i>: No Need for Amniocentesis Test Information</li> </ul>

Conversations with Family Members: Family (Fear) Narratives & Family Social Support	<ul style="list-style-type: none"> <li>• <i>“My Cousin Had the Test Done and Got a False Positive”</i>: Risk, Complications, and Family Fear Narratives</li> <li>• <i>“If My Baby Had a Problem, I Know My Family Would Help”</i>: Family Support</li> </ul>
Religious & Spiritual Values	<ul style="list-style-type: none"> <li>• <i>“Prayers Are More Powerful than Any Sort of Testing”</i>: Direct Religious Influence</li> <li>• <i>“It Could’ve Been Because of My Religion, But...”</i>: Indirect Religious Influence</li> <li>• <i>“No, My Religion Had Nothing to Do With It”</i>: No Religious Influence</li> </ul>
<b>Relationships with Healthcare Providers</b>	
Physicians’ Role in the Amniocentesis Decision	<ul style="list-style-type: none"> <li>• <i>“I Just Went With the Flow”</i>: Reciprocal Communication</li> <li>• <i>“He Just Wouldn’t Lay Off!”</i>: Pressure to Consider the Amniocentesis Procedure</li> <li>• <i>“My Doctor Didn’t Even Offer It to Me!”</i>: No Mention of the Amniocentesis Procedure</li> </ul>
Satisfactory Relationships with Healthcare Providers	<ul style="list-style-type: none"> <li>• <i>“I Felt like I Was Talking to a Family Member”</i>: The Caring/Personalismo Communicative Style</li> <li>• <i>“We Had a Very Open Line of Communication”</i>: Information-giving &amp; Listening</li> </ul>
Unsatisfactory Relationships with Healthcare Providers	<ul style="list-style-type: none"> <li>• <i>“She Was Rough, Very Rough”</i>: The Rough Physician</li> <li>• <i>“I Was Just Another Number”</i>: The Impersonal Physician</li> <li>• <i>“My Doctor Was an In-and-out Doctor”</i>: Lack of Communication and Explanation</li> </ul>